

A Resource Packet for Parents of Children with Developmental Delays

Prepared by Hospital to Home Focus Group
King County Interagency Coordinating Council

June, 1996 Edition

THIS “RESOURCE” PACKET

The purpose of this “Resource” packet is to provide valuable information for parents of children with medical needs. It was put together by people representing a variety of professions and walks of life: parents, nurses, social workers, educators, therapists, case managers, and administrators. Over a period of time, small work groups of the Hospital-to-Home Focus Group (of the King County Interagency Coordinating Council) met to develop sections of this packet. It was initially assembled in March, 1991, with revisions/expansions in April, 1992, January, 1993, and January, 1996.

The Hospital-to-Home Focus Group first met in April, 1989, to discuss planning and funding in-home nursing or attendant care for children with developmental disabilities. The fourth meeting was in November, 1989, with 40 people representing parents, home health care companies, hospitals, the public health department, schools, foster care programs, child development centers, state services, parent support groups, county mental health and developmental disabilities programs, and private insurance case management. At this meeting **parents** presented strong and positive recommendations to the group, which resulted in the development of this packet of information.

Your written comments and suggestions are solicited as you read and use this packet. Revisions will be made periodically. If you have comments or suggestions, please contact:

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Thank you, and a special thanks to all who helped put together this packet.

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"ALPHABET SOUP" - Learning the Lingo: a guide to frequently-used and sometimes confusing acronyms. Learn your way through the "jargon maze."

ACLU	American Civil Liberties Union
ABA	American Bar Association
ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
AFDC	Aid to Families of Dependent Children
AIDS	Acquired Immune Deficiency Syndrome
ALJ	Administrative Law Judge
The ARC	The ARC of King County (formerly Association for Retarded Citizens/ARC)
ARC-PC	Association for Retarded Citizens of Pierce County
ARNP	Advanced Registered Nurse Practitioner
BD	Behavioral Disability
CAP	Client Assistance Project
CD	Communication Disorder
CDC	Child Development Center
CDMRC	Child Development and Retardation Center, U.W., now CHDD
CDS	Communication Disorders Specialist (Speech Therapist)
CEC	Council for Exceptional Children
CFR	Code of Federal Regulations
CHAP	Children Have a Potential (Air Force handicap assistance program title)
CHDD	Center on Human Development and Disabilities (formerly CDMRC)
CHMC	Children's Hospital & Medical Center
CICC	County Interagency Coordinating Council
CP	Cerebral Palsy
CPS	Child Protective Services
CRSA	Community Residential Services Association
CSHCN	Children with Special Health Care Needs program
CSO	Community Service Office/DSHS
DAC	Disabled Adult Child Benefits
DC	Developmental Center
DCFS	Division of Child & Family Services/DSHS
DD	Developmentally Delayed or Developmental Disability
DDD	Division of Developmental Disabilities/DSHS
DDPC	Developmental Disabilities Planning Council
DH	Developmentally Handicapped (3-5 yr-old funding label)
DOE	Department of Employment
DOH	Department of Health (state)
DSB	Department of Services for the Blind
DSHS	Department of Social & Health Services (WA state)

DVR	Division of Vocational Rehabilitation
ECEAP	Early Childhood Education and Assistance Program
EEG	Electroencephalogram
EEOO	Equal Employment Opportunity Office
EEU	Experimental Education Unit (UW)
EHA	Education for the Handicapped Act of 1975
ECG/EKG	Electrocardiogram
EMS	Emergency Medical Services Division of SKCDPH
ESD	Educational Service District
FAPE	Free Appropriate Public Education
FHA	Federal Housing Administration
FISP	Family Individual Service Plan
FY	Fiscal Year
GAU	General Assistance Unemployable
GCDI	Governor's Committee on Disability Issues
GED	General Equivalency Diploma
HB	House Bill (legislation Washington state)
HHS	Health and Human Services
HI	Hearing Impaired or Health Impaired
HMC	Harborview Medical Center
HRC	Human Rights Commission
HUD	Housing and Urban Development
IDEA	Individuals with Disabilities Education Act
IEP	Individual Education Program
IFSP	Individualized Family Service Plan
IHP	Individual Habilitation
IPP	Individual Program Plan
ISP	Individual Service Plan
ITEIP	Infant & Toddler Early Intervention Program
IWRP	Individual Written Rehabilitation Plan
I&R	Information and Referral
KCHS	King County Human Services
KCICC	King County Interagency Coordinating Council
LD	Learning Disability
LDA	Learning Disabilities Association
LEA	Local Education Agency
LEAA	Law Enforcement Assistance Administration
LLD	Learning Language Disability
LRE	Least Restrictive Environment
MAMC	Madigan Army Medical Center
MBD	Minimal Brain Dysfunction

MD	Muscular Dystrophy
MDT	Multidisciplinary Team
MMR	Mild Mental Retardation
MR	Mental Retardation
MS	Multiple Sclerosis
NI	Neurologically Impaired
NRA	National Rehabilitation Association
OCR	Office for Civil Rights
OSERS	Office of Special Education and Rehabilitative Services
OSPI	Office of the Superintendent of Public Instruction
OT	Occupational Therapy/Therapist
P&A	Protection and Advocacy system
PAC	Parent Advisory Council
PAVE	Parents Advocating for Vocational Education
PHN	Public Health Nurse
PL	Public Law
PPP	People for Positive Parenting
PPS	Pupil Personnel Services
PT	Physical Therapy/Therapist
PTA	Parent Teacher Association
RCW	Revised Code of Washington
REW	Rehabilitation Enterprises of Washington
RHC	Residential Habilitation Center
RSA	Rehabilitation Service Administration
SB	Senate Bill (Washington State)
SBD	Severe Behavioral Disability
SICC	State Interagency Coordinating Council
SKCDPH	Seattle-King County Department of Public Health
SCIA	Special Children's Intervention Association
SEA	State Education Agency
SEPAC	Special Education Parent Advisory Council
SIDS	Sudden Infant Death Syndrome
SLD	Specific Learning Disability
Sp.ED	Special Education
SPI	Superintendent of Public Instruction
SSA	Social Security Administration
SSDI	Social Security Disability Income
SSI	Supplemental Security Income (for the disabled)
STD	Sexually Transmitted Disease
STOMP	Specialized Training of Military Parents
SW	Social Work/Worker

TACID	Tacoma Area Coalition of Individuals with Disabilities
TASH	The Association for Persons with Severe Handicaps
TLC	Tacoma Learning Center/Tacoma Learning Community/Therapeutic Learning Center
TDD	Telecommunication Devices for the Deaf
TTY	Telecommunication Device for the Deaf, Hearing-Impaired, and Speech-Impaired
UAP	University Affiliated Programs
UCP	United Cerebral Palsy
VA	Veterans' Administration
VI	Visually Impaired
WAC	Washington Administrative Code (legislation)
WACD	Washington Assembly for Citizens with Disabilities
WACLD	Washington Association for Children and Adults with Learning Disabilities
WAEHI	Washington Association for the Education of the Hearing Impaired
WAEVI	Washington Association for the Education of the Visually Impaired
WAMI	Washington Advocates for the Mentally Ill
WANSAC	Washington Chapter of the National Society for Children and Adults with Autism
WaSHIF	Washington State Head Injury Foundation
WCCD	Washington Coalition of Citizens with Disabilities
WCLD	Washington Council for Learning Disabilities
WIC	Women, Infants, and Children Supplemental Food Program
WORD	Washington Organization for Reading Development
WSPEP	Washington State Parent/Educator Partnership Project

PARENTS' PERSPECTIVES

- **“From Parents”**
- **“What Happened”**
by Julie Fleisch
- **"You Are Not Alone: For Parents When They Learn That Their Child Has a Handicap"**
by Patty McGill Smith
- **"Working with Professionals"**
by Robin Simmons

1. From Parents

Vicki: (mom of a blind infant)

We thought our whole life would be different...and it's not. All the professional things you have to do--doctors and therapy and all. Our strengths were our family (especially mine) and the support of my husband. About support groups, GO and go more than once because the first one made me feel worse and then they got better and better. I hope I can be there for someone else, because that would have been so helpful for me to meet another family with a child the same as mine.

Edrie: (mom of a child born with severe kidney disease)

Take a deep breath and soak it all in. I was in shock for a long time. I was in shock in the hospital. Talking to the doctors and having them give me as much information as I could handle, that was the most helpful thing. It's nice to know what to expect. I started to worry that he would die. They were worried about his high creatinine levels (kidney tests) and not that he would die right away. If it's not as bad as you think, then you can get under control. Use the Head Nurse to talk to if you can't get to the doctor--someone to bounce things off of. Get information to calm yourself and help you to deal with it. Look at what's normal in your child.

Camille & Rick: (parents of a child with Down syndrome with heart disease)

I let Camille be the reader and she told me everything. She read all she could get her hands on. Talking to other parents would be helpful. We feel we've learned so much in nine months, we would like to share with another family. We've thought all about therapy, school and even if we would need a little house out in back for her 20 years from now if she can't live alone. There's so many children like her out there that people don't even know about. We didn't until Jenna came along. And you make a whole new set of friends in the nurses, therapists, and doctors you meet. We had problems with some of the family but our friends were wonderful. Support groups are helpful, too. We interviewed all the available early intervention schools and picked the best one for our needs. We are very open in talking about her to friends and all. It was important for me to breast feed her like I had for her brother and sister, it made it easier to cope with all the changes/differences.

Laura: (mom of a very premature child, oxygen dependent for a long time)

I was not attached at all for the first one and a half months, I wouldn't touch her until the doctors were hopeful. I didn't want to get attached. So I guess I didn't cope at all at first. Lots of issues around her prematurity were part of my worries. Losing my job due to my pregnancy and financial concerns may have contributed to the prematurity. Then I had to know everything there was to taking care of her and I did all of her care for hours after my husband was off work every night. It was a long drive from our house. The hospital was our life for four months. I was ready to get her home before the doctors were. No one is ever really ready, physically ready maybe, but not emotionally. Most of my support came from my family. I got support from my private doctor. He took time to treat us as a family, not just as a premature child.

Raisin: (mom of a preschooler with leukemia)

Lots of shock. I heard the first word--cancer--- and then nothing. I had to ask over and over to hear all the information. I think they got tired of hearing me ask the same things. My biggest support was from co-workers at work. They knew how I felt about what was happening.

Richard & Sheri: (parents of a preschooler with leukemia)

Our best support came from each other. Richard asks all the questions and keeps track of the "counts" (lab values) and protocols and Sheri gets lots of support from her mother, daily phone calls. We got the name of another family in North Carolina and wrote them because their child had the same diagnosis and they called us one Sunday and we talked. That helped very much to talk to them. We get all the information we need from the clinic and keep track of questions in a little notebook so we don't forget by the next appointment. Our son acts so normal that sometimes we wonder if they got the wrong kid.

Sheri: (mom of twins, one with serious neurological problems)

No one wanted to diagnose or admit my child had a problem so I denied it all too. We didn't know she was high risk, and felt it would all work out. The doctor said it could be this or that or could be normal--I clung to that one. I was an engineer and a planner and this didn't fit into the plans. Reading was the most helpful. I didn't and still don't want to meet with other families --it's okay for others, but it doesn't work for everyone. My mom came and moved in for five months to help until both girls were discharged. If anyone offers help, take it--anything, food, babysitting, anything helps. I believe where there's life there's hope and I lived with that and it helped. My best resource was my Public Health Nurse and her resources, therapy, classes, etc. I also had support of spouse and family.

2. What Happened!

by Julie Fleisch

When my son Colin was born it was the happiest day of my life. My husband and I both had successful careers, had purchased our house, and had our lives well organized. I had spent the summer hiking and, physically, felt good except for my growing middle. Colin was born on a fall evening after a long day of hard, induced labor. Both my husband and I were euphoric about this beautiful, absolutely perfect little boy that we had created. He was 8 lbs. 3 oz.s. and had no flaws that we could see. The world was a pretty great place!

Twenty-four hours later our world came crashing down. They were working pretty hard to resuscitate him when we found them in the nursery. Within an hour the team arrived via ambulance to encase him in a glass box, tubes down his airway and the machine breathing in and out. There was a lot of confusion about what happened--why --but mostly I felt the worst I've ever felt.

The next morning, my doctor arranged for me to transfer to the hospital where Colin was taken. We became familiarized with the NICU routine, washing our hands for 10 minutes, gowning up, the portholes we reached through to touch our beautiful son, and seeing the other babies.

I walked around in a daze--there were a lot of tears and a lot of hours just sitting, feeling very very down. When I went home, I would sit in his room and just stare at the empty crib. I didn't even want to hold him when we visited the NICU after the first time he stopped breathing as I held him. He didn't seem to belong to me anymore. The hospital was in control. The rest of the world didn't even exist for me during those first few weeks.

Slowly I began to organize myself. The tears came less often and the hurt became less obvious. I felt angry instead; angry that this had happened to upset my world, our world, his world. I was angry that these doctors were, without thought, cutting holes in my perfect little baby--he was not beautiful anymore. I was angry that they could tell me such horrible news--that my son had brain damage - so easily. I was angry at my husband--I don't know why, maybe he didn't love this little boy as much as I did or maybe he was just there to be angry at. I searched for answers as to why this had happened. Had I wanted a baby too much or had I somehow done something wrong and this was my pay back? When a cause isn't readily evident we place guilt where it seems to fit best.

When he finally came home we learned what the word exhaustion really meant. Colin wouldn't sleep, had to be suctioned, gavage fed, and there were no breaks. I had to drag myself through the routine. I would dream about running away. Maybe it would all go away somehow. But it didn't and we survived.

Time has eased the emotional turmoil. I no longer wake up in the morning and think of it first thing. I no longer search for reasons why. I have become positive and productive again and I am a good parent. My son is still a large part of my life and though I wouldn't want this experience to happen to anyone, I can say that I wouldn't trade him for anything. It has taken me a long time to get to this point. I have learned some things about myself and how I cope with sorrow and stress. I allow myself some releases through humor and tears at times and most importantly some times to just forget it all for awhile. I have learned to love my son for himself, not for what we had hoped or dreamed for him. I have learned that it's important to give back some of my new knowledge about special needs and children. I talk a lot with other parents who have similar experiences, both at support groups and just people I meet. After all--the day my son, Colin, was born was the happiest day of my life.

3. You Are Not Alone: For Parents When They Learn That Their Child Has a Handicap

by Patty McGill Smith

If you have recently learned that your child is developmentally delayed or has a handicapping condition, which is or is not completely defined, this message may be for you. It is written from the personal perspective of a parent who has shared this experience and all that goes with it.

When parents learn about any difficulty or problem in their child's development, this information comes as a tremendous blow. The day my child was diagnosed as having a handicap, I was devastated--and so confused that I recall little else about those first days other than the heartbreak. Another parent described this event as a "black sack" being pulled down over her head, blocking her ability to hear, see, and think in normal ways. Another parent described the trauma as "having a knife stuck" in her heart. Perhaps these descriptions seems a bit dramatic, yet it has been my experience that they may not sufficiently describe the many emotions that flood parents' minds and hearts when they receive any bad news about their child.

Many things can be done to help a parent through this period of trauma. That is what this paper is all about. In order to talk about some of the good things that can happen to alleviate the anxiety, let us first take a look at some of the reactions that occur.

Common Reactions

On learning that their child may have a handicap, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and with this enormous challenge. One of the first reactions is that of denial--"this cannot be happening to me, to my child, to our family." Denial rapidly merges with anger, which may be directed toward the medical personnel who were involved in providing the information about the child's problem. Anger can also color communication between husband and wife or with grandparents or significant others in the family. Early on, it seems that the anger is so intense that it touches almost anyone, because it is triggered by feelings of grief and inexplicable loss that one does not know how to explain, nor how to deal with.

Fear is another immediate response. People often fear the unknown more than they fear the known. Having the complete diagnosis and future prospects can be easier than uncertainty. In either case, however, fear of the future is a common emotion: "What is going to happen to this child when he is five years old, when he is twelve, when he is twenty-one? What is going to happen to this child when I am gone?" Then other questions arise: "Will he ever learn? Will he ever go to college? Will he or she have the capability of loving and living and laughing and doing all the things that we had planned?"

Other unknowns also inspire fear. Parents fear that the child's condition will be the very worst that it possibly could be. Over the years, I have spoken with so many parents who said that their first thoughts were totally bleak. One expects the worst. Memories return of handicapped persons one has known. Sometimes there is guilt over some slight committed years before toward a handicapped person. There is also fear of society's rejection, fears about how brothers and sisters will be affected, questions as to whether there will be any more brothers and sisters in this family, and concerns about whether the husband or wife will love this child. These fears can almost immobilize some parents.

Then there is guilt--guilt and concern about whether the parents themselves have caused the problem: "Did I do something to cause this? Am I being punished for having done this? Did I take care of myself when I was pregnant? Did my wife take good enough care of herself when she was pregnant?" For myself, I remember thinking that surely my daughter had slipped from the bed when she was very young and hit her head, or that perhaps one of her brothers or sisters had inadvertently let her drop and didn't tell me. Much self-reproach and remorse can stem from questioning the causes of the handicap.

Guilt feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, "Why me?", or "Why my child?", many parents are also saying, "Why has God done this to me?" How often have we raised our eyes to heaven and asked: "What did I ever do to deserve this?" One young mother said, "I feel so guilty because all my life I had never had a hardship and now God has decided to give me a hardship."

Confusion also marks this traumatic period. As a result of not fully understanding what is happening and what will happen, confusion reveals itself in sleeplessness, inability to make decisions, and mental overload. In the midst of such a trauma, information can seem garbled and distorted. You hear new words that you never heard before, terms that describe something that you cannot understand. You want to find out what it is all about, yet it seems that you cannot make sense of all the information you are receiving. Often parents are just not on the same wavelength as the person who is trying to communicate with them about their child's handicap.

Powerlessness to change what is happening is very difficult to accept. You cannot change the fact that your child is handicapped, yet parents want to feel competent and capable of handling their own life situations. It is extremely hard to be forced to rely on the judgments, opinions, and recommendations of others. Compounding the problem is that these others are often strangers with whom no bond of trust has yet been established.

Disappointment that a child is not perfect poses a threat to many parents' egos and a challenge to their value system. This jolt to previous expectations can create reluctance to accept one's child as a valuable, developing person.

Rejection is another reaction that parents experience. Rejection can be directed toward the child or toward the medical personnel or toward other family members. One of the more serious forms of rejection, and not that uncommon, is a "death wish" for the child--a feeling that many parents report at their deepest points of depression.

During this period of time when so many different feelings can flood the mind and heart, there is no way to measure how intensely a parent may experience this constellation of emotions. Not all parents go through every one of these stages, but it is important for parents to identify with all of the potentially troublesome feelings that can arise so that they will know that they are not alone. There are many constructive actions that you can take immediately, and there are many sources of help, communication, and reassurance.

Seek the Assistance of Another Parent

There was a parent who helped me. Twenty-two hours after my own child's diagnosis, he made a statement that I have never forgotten: "You may not realize it today, but there may come a time in your life when you will find that having a daughter with a handicap is a blessing." I can remember being puzzled by these words, which were nonetheless an invaluable gift that lit the first light of hope for me. This parent spoke of hope for the future. He assured me that there would be programs, there would be progress, and there would be help of many kinds and from many sources. And he was the father of a retarded boy.

My first recommendation is to try to find another parent of a handicapped child, preferably one who has chosen to be a parent helper, and seek his or her assistance. All over the United States and over the world, there are Parent-Helping-Parent Programs. The National Information Center for Handicapped Children and Youth has listings of parent groups that will reach out and help you. If you cannot find your local parent organization, write to the National Information Center [listed at the end of this article] to get that local information.

Talk with Your Mate

Over the years, I have discovered that many parents don't communicate their feelings regarding the problems their children have. One spouse is often concerned about not being a source of strength for the other mate. The more couples can communicate at difficult times like these, the greater their collective strength.

If there are other children, talk with them, too. Be aware of their needs. If you are not emotionally capable of talking with your children or seeing to their emotional needs at this time, identify others within your family structure who can establish a special communicative bond with them. Talk with significant others in your life--your best friend, your own parents. For many people, the temptation to close up is great at this point, but it can be so beneficial to have reliable friends and relatives who can help to carry the emotional burden.

Rely on Positive Sources in Your Life

One positive source of strength and wisdom might be your minister, priest, or rabbi. Another might be a good friend or counselor. Go to those who have been a strength before in your life. Find the new sources that you need now.

A very fine counselor once gave me a recipe for living through a crisis: "Each morning, when you arise, recognize your powerlessness over the situation at hand, turn this problem over to God, as you understand Him, and begin your day."

Whenever your feelings are painful, you must reach out and contact someone. Call or write or get into your car and contact a real person who will talk with you and share that pain. Pain divided is not nearly so hard to bear as is pain in isolation. Sometimes professional counseling is warranted; if you feel that this might help you, do not be reluctant to seek this avenue of assistance.

Take One Day at a Time

Fears of the future can immobilize one. Living with the reality of the day which is at hand is made more manageable if we throw out the "what if's" and "what then's" of the future. Good things continue to happen each day. Take time to "smell the roses."

Learn the Terminology

When you are introduced to new terminology, you should not be hesitant to ask what it means. Whenever someone uses a word that you don't understand, stop the conversation for a minute and ask the person to explain the meaning.

Seek Information

Some parents seek virtually "tons" of information; others are not so persistent. The important thing is that you request accurate information. You should not be afraid to ask questions, because asking questions will be your first step in beginning to understand more about your child. Learning how to formulate questions is an art that will make life a lot easier for you in the future. A good method is to write down your questions before entering appointments or meetings, and to write down further questions as you think of them during the meeting. Get written copies of all documentation from physicians, teachers, and therapists regarding your child. It is a good idea to buy a three-ring notebook in which to save all information that you have recorded and filed; keep it in a safe place. Again, remember always to ask for copies of evaluations, diagnostic reports, and progress reports.

Do Not Be Intimidated

Many parents feel inadequate in the presence of people from the medical or educational professions because of their credentials. Do not be intimidated by the educational backgrounds of these and other personnel who may be involved in treating or helping your child. You do not have to apologize for wanting to know what is occurring. Do not be concerned that you are being a bother or are asking too many questions. Remember, this is your child, and the situation has a profound effect on your life and on your child's future. Therefore, it is important that you learn as much as you can about your situation.

Do Not Be Afraid to Show Emotion

So many parents, especially dads, repress their emotions because they believe it to be a sign of weakness to let people know how badly they are feeling. The strongest fathers of handicapped children whom I know are not afraid to show their emotions. They understand that revealing feelings does not diminish one's strength.

Learn to Deal with Bitterness and Anger

Ultimately, bitterness and anger will hurt you a great deal more than they will affect those toward whom the anger is directed. It is very valuable to be able to recognize your anger and then let go of it. It is understandable that parents will be bitter and angry and disappointed to learn that their child has a serious problem. When you realize that these negative responses tend to hurt you and make you less effective with your child, you can decide to do something about them. Life is better when you are feeling positive. You will be better equipped to meet these new challenges when bitter feelings are no longer draining your energies and initiative.

Adopt a Grateful Attitude

It is hard to remain angry when one is grateful. Sometimes, when everything seems to be going wrong, it is difficult to find a cause for gratitude. However, in the scheme of things, if you look around and count your blessings, perhaps positive feelings can overtake the more negative ones.

Maintain a Positive Outlook

A positive attitude will be one of your genuinely valuable tools for dealing with problems. There is truly always a positive side to whatever is occurring. For example, when my child was found to be handicapped, one of the other things pointed out to me was that she was (and still is) a very healthy child. The fact that she has had no physical impairments has been a great blessing over the years; she has been the healthiest child I have raised.

Keep in Touch with Reality

To stay in touch with reality is to accept life the way it is. To stay in touch with reality is also to recognize that there are some things that we can change and other things that we cannot change. The task for all of us is learning which things we can change and then to set about doing that.

Remember That Time is on Your Side

Time heals many wounds. This does not mean that living with and raising a child who has problems will be easy, but it is fair to say that, as time passes, a great deal can be done to alleviate the problem. Therefore, time does help!

Find Programs for Your Child

Even for those living in isolated areas of our country, assistance is available to help you with whatever problems you are having. [Please see the "Family Resources" section of this packet.] While finding programs for your handicapped child, keep in mind that programs are also available for the rest of your family, too.

Take Care of Yourself

In time of stress, each person reacts in his or her own way. A few universal recommendations may help: get sufficient rest; eat as well as you can; take time for yourself; reach out to others for emotional support.

Avoid Pity

Self-pity, the experience of pity from others, or pity for your child are actually disabling. Pity is not what is needed. Empathy, which is the ability to feel with another person, is the attitude to be encouraged.

Avoid Judgments

During this period, parents may become judgmental about the way people are reacting toward them or toward their child. Many people's reactions to serious problems are based on a lack of understanding, fear of knowing what to say, or fear of the unknown. Therefore, others may sometimes react inappropriately, but you need not use too much energy in being concerned over those who are not able to respond in ways that you might prefer.

Keep Daily Routine as Normal as Possible

My mother once told me, "When a problem arises and you don't know what to do, then do whatever it was that you were going to do anyway." Practicing this habit seems to produce some normalcy and consistency when life becomes hectic.

Remember That This Is Your Child

This person is your child, first and foremost. Granted, you child's development may be different from that of other children, but this does not make your child less valuable, less human, less important, or less in need of your love and parenting. Love and enjoy your child. The child comes first; the handicapping condition is second. If you can relax and take the positive steps just outlined, one at a time, you will do the best you can, your child will benefit, and you can look forward to the future with hope.

Recognize That You Are Not Alone

The feeling of isolation at the time of diagnosis is almost a universal feeling among parents. In this paper, there are many recommendations to help diminish those feelings of separateness and isolation. You can diminish these feelings by recognizing that they have been experienced by many, many others, that understanding and constructive help are available to you and your child, and that you are not alone.

This article is reprinted with permission from NICHCY, the National Information Center for Children and Youth with Disabilities, P.O. Box 1492, Washington, D.C. 20013, telephone (toll-free) 1-800-999-5599. A copy of NICHCY's "Publications List 1991" is in the "Family Resources" section of this packet.

4. Working with Professionals

(from "After the Tears" by Robin Simmons)

A child's disability brings parents into contact -- and sometimes into conflict -- with doctors, teachers, and therapists. Here are suggestions for developing partnerships with professionals to foster the best care for your child.

1. **Develop positive communications skills.** It's easy for the relationship to become adversarial, but that's counterproductive. You make it easier for professionals to give you what you need if you communicate with them positively.
 - a) Be assertive but not aggressive. Say what you believe firmly, but not with anger or implied threats. Your goal is to get them to listen -- not make them defensive.

- b) Listen. It's easy to spout a list of grievances. But if you don't listen to the professionals, you can't expect them to listen to you. Your goal is open communication.
 - c) Act rational. Dealing with professionals prompts a lot of emotions. Most professionals understand that. Still, the more rational you can be with them, the more willing they'll be to listen.
2. **Find a doctor you can talk to.** You don't have to stay with a doctor you don't like. "Shop around" until you find one you feel comfortable with. Not all doctors feel comfortable with disabilities. Not all doctors are willing to talk about your feelings. Some give parents a lot of information and encourage participation in decisions, others don't. Decide what kind of relationship you want with your doctor and find one who will work with you that way.

As with any two people, sometimes personalities "click" and sometimes they don't. Find a doctor you can talk to easily. As Jo Lynn Lei says, "Good communication is worth waiting a long time in the waiting room for."

Don't feel shy about interviewing a doctor. You hire him to perform a service for you; you should be happy with the service you get. Kathy Taylor: "As soon as a doctor tells me she's 'typical,' we leave him. I won't stay with a doctor I don't like. I look for the ones who treat me and my kids the way I want to be treated. When I interview a doctor I ask, 'Have you ever dealt with a child who has Down Syndrome before?' If he says 'yes' and implies that all Down kids are similar, I won't go to him. If he says, 'No, but I'll give it a shot,' that's good. You can tell a lot about a doctor's attitude at an interview."

You won't communicate equally well with all doctors who serve you. Find one with whom you do feel comfortable and ask if he'll help you work with the others.

Hopefully, he'll also give you some emotional support. But that's not the doctor's primary role. A parents group or counselor can better meet that need. The intense anger parents feel toward professionals is frequently a spillover of other anger, guilt and sadness at having a child with a disability. Counseling can help you come to terms with those latent feelings.

3. **You are your child's expert: tell them what you know.** You know your child better than anyone. You know what's normal for him. You see sides of him professionals never see. Your gut instincts about what your child needs are correct. Trust them.

Carol Knibbs: "Time after time I'd go into the doctor or the school and tell them what I thought my daughter needed. They'd tell me I was wrong. At first I'd believe them. Then it would turn out to be right. After years of this I finally caught on -- I know more about Marti than they do."

Because professionals see only a small part of your child, they need to hear about what you see at home. Insist they listen. That's not easy: we're trained to see professionals as authority figures who know everything. But they don't; they're only human. So don't be afraid to assert yourself.

Lois Lanier was told by the school that her six-year-old daughter could not read. Lois knew Carrie could read because she saw her reading product names which she had learned from TV. So she made an appointment to speak with Carrie's teacher. When the teacher refused to believe that Carrie read at home, Lois brought out a stack of flash cards. As she flashed each card, Carrie read it correctly. The teacher said, "She's got them memorized in order." Undaunted, Lois shuffled the cards and flashed them again. Carrie still read them correctly. Lois's advice: "Don't be afraid to tell professionals what you see at home."

4. **Be prepared.** Maximize your time in the office by doing your homework first:
 - a) Read about your child's condition. Since library books are frequently outdated, ask your professionals or parents group for a current reading list.
 - b) Make a list of your questions before you go. It will help you remember what you'd planned to ask.
 - c) If you have a particular concern about your child's health or behavior, keep a log for a few days before you go. Record the frequency and duration of symptoms, plus anything you've done to treat them. This will help the professional diagnose the situation.
5. **Stick to the topic.** A professional schedules time based on what you tell him you need. If, during an appointment, you bring up an "unscheduled" issue, he may not have time to discuss it, and, as a result, may seem hurried or brusque. You can avoid this by stating all your concerns at the beginning of the appointment. If there are unscheduled items, make an appointment to discuss those at another time. Both appointments will be smoother.
6. **Speak up ... nicely.** If you have a problem with what a professional has told you, don't be afraid to say so. If you'd like a second opinion, say "Might someone else in your field feel differently?" Your doctor won't mind; second opinions are common. If you can't squeeze in another therapy at night, ask if there's a different way to get the practice in. Your therapist will help you find one. Work with your professionals to provide the services your child needs.
7. **Say "no" to therapy... occasionally.** "The speech therapist says, 'Do half an hour of therapy after dinner.' The physical therapist says, 'Do 30 minutes of therapy in your spare time.' What spare time?! I have two other kids and a husband! I finally said 'no' to all that therapy. I had to choose between being my child's extension therapist and being his mother. And I chose being his mother."

There are times when even an acceptable amount of therapy becomes too much--when your child needs time to be a child, or when you need time to be with the rest of the family. It's OK to say "no" at those times, for a while. Your instinct will tell you when.

8. **Form a partnership.** Professionals are people, too. They have good days and bad days. They work long hours that are emotionally draining. They've chosen their profession because they care deeply about children, and nurse the same hopes for your child that you do. You each have your own -- partial -- expertise. Together you form a complete team. Make that teamwork happen. You are as much responsible for it as the professionals. If you want them to be "real" with you, be "real" with them. As one doctor said, "Sometimes a little reverse sympathy is very much appreciated. A simple remark like, 'Gee, it looks like you had a tough night,' goes a long way. It solidifies the emotional bond between us."

Eula Boelke says it simply: "I make friends with the people who serve my child."

HOME HEALTH CARE

- **Home Health Care Services**
- **Home Health Care Companies**
- **Things for Your Family to Think About in Planning Home Health Care**
- **Questions from Prospective Home Health Care Companies**
 - *in General*
 - *Regarding Treatment*
 - *Regarding Hiring and Training of Health Care Providers*
 - *Regarding Cost*
- **Medical Supplies and Equipment**
- **Home Health Care Suppliers**
- **Questions of Suppliers**

1. Home Health Care Services

Many children with a serious medical condition, even those on life-support systems, may be discharged from the hospital to the family home when medical or nursing services, supplies, and equipment can be provided in the home. Home-based medical or nursing care is usually much less expensive than hospital care and is thus very desirable from a financial viewpoint, as well as for the welfare of the child and family. Home health care companies provide medical or nursing services in the home and can be funded in a variety of ways.

Home health care companies are private businesses, either for-profit or not-for-profit, which provide nursing and related services primarily in private homes or apartments. Some companies are operated nationwide, and others are locally or regionally owned and operated. They hire and train registered nurses (RN) and licensed practical nurses (LPN) for in-home care. In addition, some companies hire and train under RN supervision certified nurse's aides (CNA) or home health aides (HHA) to provide attendant care. They may also have social workers (MSW-master of social work) and various therapists (physical [PT], occupational [OT], and speech).

Home health care companies may serve all ages, only children, or only adults. All provide shift care (with minimums of one or more hours per day), and in addition some provide intermittent care (on occasion or several times a week).

They are paid **personally**, by private **insurance**, by **Medicare** or **Medicaid**, by the Washington State **D**elartment of **L**abor and **I**ndustries (DLI or **L&I**) and/or **D**elartment of **S**ocial and **H**ealth **S**ervices (**DSHS**). Within DSHS, there are three different divisions which may pay for in-home nursing care, depending on which program the child qualifies for: the **D**ivision of **D**evelopmental **D**isabilities (**DDD**), the **M**edical **A**ssistance **A**dministration (**MAA**), and the **D**ivision of **C**hildren and **F**amily **S**ervices (**DCFS**). Hospital social workers may be a resource for programs which will pay for in-home nursing care.

The next page provides information about some home health care companies and their services. See the yellow pages of your telephone directory for more companies.

2. Home Health Care Companies

Be sure to refer to the pages noting things to think about in planning home health care and questions for home health care companies. Some of the companies listed specialize in the care of children, while others serve all ages. Most accept payment from Division of Developmental Disabilities (DDD), Medicaid/medical coupons, and other insurance. All use registered nurses, plus a variety of other health care providers such as licensed practical nurses, nurses aids, physical therapists, occupational therapists, respiratory therapists, or social workers. Make a list of your own questions before talking with providers.

Acute Care, Inc.

14615 NE North Woodinville Way, Suite 108
Woodinville, WA 98072
483-3303

Care Professionals

13804 NE 175th Suite #B
Woodinville, WA 98072
487-6777

Medical Personnel Pool of Seattle, Inc.

2033 6th Ave. #310
Seattle, WA 98121
443-7665

NSI Services, Inc.

300 Elliot Ave. West, Suite 550
Seattle, WA 98119
285-6132

Pediatric Home Care

13400 Northup Way #42
Bellevue, WA 98005
747-7161 or 1-800-564-1906

Visiting Nurse Services of the Northwest

400 No. 34th
Seattle, WA 98103
548-8100 or 1-800-422-5798

Alternative Rehab Home Healthcare

6000 Southcenter Blvd., Suite 250
Seattle, WA 98188
246-1221 or 1-800-273-ARHH

Olsten Kimberly Quality Care

155 NE 100th, Suite 306
Seattle, WA
1-800-244-2782

New Care Concepts, Inc.

2208 NW Market St., Suite 510
Seattle, WA 98107
789-9054 or 1-800-635-6480

Nurse's House Call

10303 Meridian Ave. No., Suite 203
Seattle, WA 98133
524-1096

Staff Builders

10740 Meridian Ave. No. #102
Seattle, WA 98133
364-0535 or 1-800-258-1059

3. Things for Your Family to Think About in Planning Home Health Care

The goal of getting your child home is to rejoin the family. Remember there will be differences in the environment between hospital and home.

How do you communicate the best (in writing or by discussion) regarding conflicts, care issues with your child, employer/employee expectations?

Identify who will be the main spokesperson for the family.

Do you need help in determining if your home can accommodate your child, equipment and personal needs?

What is the most ideal place for your child in your home? Consider family privacy, accessibility, etc.

Is the immediate environment your child will be in self-sufficient? For example, comfortable surroundings, supplies, medications readily available.

What child-related care activities would be helpful to you for the staff to perform? For example, meal/formula preparation, laundry, equipment/supply ordering and cleaning, bathing, etc.

Do you have any special requests of the employees particular to your family/personal needs? For example, involvement with siblings, use of kitchen and other household areas, etc.

Consider extra environmental costs and space: water, lighting, heat, electrical outlets, comfortable chair, parking access to home, telephone, refrigerator, storage space, microwave, etc.

Prior to taking your child home, planning will need to be done toward identifying community physicians and support: talk with parents of other medically fragile children; call KidCare/Community Health Access Program (284-0331 or 1-800-756-5437); talk with your hospital medical staff; utilize your local health department (Children with Special Health Care Needs program and public health nurses); and/or talk with your insurance company's case manager.

Each parent's and care provider's training needs will be tailored to the individual needs of your child and will usually be coordinated by hospital nursing staff prior to discharge.

4. Questions for Home Health Care Companies

In general:

- What is a home health company and what does it provide? Is it different than a nursing service?
- Is the company Medicare and/or Medicaid certified?
- Is the company licensed and accredited? How?
- How long has the company been in business?
- Does the company have its own employees or just run a registry?
- Does the company have a brochure and/or other materials describing its services?
- Can the company help define the level of care needed (i.e., attendant, LPN, RN)? Can the company help define family needs?
- What is expected of the health care providers? What are their specific tasks? What do they do or not do?

- Does the company provide specific care plans?
- Does the company provide references (i.e., another parent)?

Regarding Treatment:

- Are the families guaranteed confidentiality of information?
- Do the families have access to the nursing progress reports?
- How much participation in the planning and giving of care is expected from the families?
- Does the company respect families' ethnic/cultural backgrounds and religious beliefs?
- Does the company provide the families with information and/or contacts for counseling?
- Does the company provide support services (i.e., OT, PT, speech)?
- Does the company work together with the families in preparing the living space of their home for this new set of circumstances?
- What kind of equipment and supplies are needed?
- Does the company provide needed supplies or help the families find a supply company?
- Are the families or health care providers in charge of ordering and maintaining supplies/equipment?
- Do families have a say in the level of interaction that the health care providers have with the children?
- What about the other children?
- Will we ever get any privacy?

Regarding Hiring and Training of Health Care Providers:

- Who screens and hires the health care providers? How is this accomplished?
- Are the health care providers thoroughly trained and oriented to specific cases?
- Do the parents choose the health care providers? What if they don't like a particular nurse?
- What happens when health care providers cancel? Does the company have back-up? Are the families expected to cover shifts?
- Does the company have a 24-hour-a-day on-call person?
- Are the health care providers bonded?
- Are the health care providers covered by liability insurance?
- Do the health care providers wear uniforms?
- Do the health care providers interact with the family? How much?

Regarding Cost:

- What is the source of payment for the company?
- Who interacts with the payor (i.e., parent, company)?
- What if there are problems with the funding source?
- How much does the company charge (per hour, per shift)?
- Are there additional costs (charges for paperwork, phone calls)?

5. Medical Supplies and Equipment

Although hospitals and home health care companies can make recommendations and assist, parents are responsible in the end for purchasing medical supplies and equipment for in-home nursing care. This is a whole new world for most parents and requires quick learning about some very complex technology. It is very important for parents to know that:

- a) The price and quality of medical supplies and equipment, and the reliability of vendors vary greatly, so "shopping around" for the best price for the best product and good customer references, is a good idea.
- b) Insurance companies need to be consulted about what they will cover and how it will be covered, so always check with them before ordering any supplies or equipment. In some cases it may be possible to bargain with insurance companies for better coverage from lower-priced suppliers.
- c) Hospitals and/or home health care companies may have a vested interest in certain suppliers, so their recommendations may not always be the best. Again, "shopping around" is always the best practice in finding out about costs, quality, and customer-service of various suppliers.

The next pages provide information about some home health care suppliers in the Puget Sound area, where they are located, and what services or supplies they offer. For other suppliers, please look in the yellow pages of the telephone book under "Pharmaceutical Products," "Medical Equipment," and/or "Medical Supplies." Or you may contact the KidCare/Community Health Access Program in Seattle for recommendations based on parents' input: 284-0331 (local) or 1-800-756-KIDS (long distance).

Finally, the last page of this section provides a list of some questions parents can ask home health care suppliers to obtain the best service. It is important to remember that any question you may have is never "too dumb" to ask and to be answered clearly and respectfully by the home health care company or supplier.

6. Home Health Care Suppliers

Most home health care suppliers provide a variety of equipment and services. The majority will accept funding from Medicaid/DSHS or other insurance. Questions to ask include whether they provide free delivery, 24 hour access, and family education about the supplies and how they are used.

Companies who provide some or all of the following: feeding equipment such as feeding pumps, feeding tubes, special formulas, formula supplements (to increase calories or to thicken to prevent aspiration), gastrostomy and other ostomy supplies, suction equipment, diapers (over age three), intravenous therapy and equipment: (this is not a complete list)

APRIA Healthcare

14935 NE 87th St
Redmond, WA 98052
881-8500 or 1-800-452-8137

Medical Supply, Inc

14522 NE North Woodinville Way, #106A
Woodinville, WA 98072
481-2446 or 1-800-506-1116

CHOICE Medical Supplies, Inc.

1215 East Union St
Seattle, WA 98122
329-1668 or 1-800-456-3500

Medi-Rent

630 SW 153rd
Seattle, WA 98166
243-4357 or 1-800-999-1027

Coram Healthcare

6645 185th Ave NE, Suite 151
Redmond, WA 98052
1-800-727-1415

National Medical Care

1331 118th Ave SE, Suite 100
Bellevue, WA 98004
453-1988

Home Health Care of Washington

2539 152nd St NE, Bldg 14 GH
Redmond, WA 98052
883-8928 or 1-800-888-1429

OPTION Care

13035 Gateway Dr, Suite 131
Seattle, WA 98168
246-0083 or 1-800-624-0226

Home Health Plus

13810 SE Eastgate Way, Suite 100
Bellevue, WA 98004
644-3027

For oxygen, monitors, pulmoaids (to provide nebulized medication directly to the lungs) and associated supplies:

APRIA Healthcare

14935 NE 87th
Redmond, WA 98052
881-8500 or 1-800-456-8445

Medi-Rent

600 SW 153rd
Seattle, WA 98166
243-4357 or 1-800-999-1027

Companies who provide wheelchairs, bath chairs, prone standers, all types of equipment for mobility and positioning:

Care Medical

4135 Stone Way No
Seattle, WA 98103
547-2200 or
1-800-952-9566

Sound Medical

34507 Pacific Hwy So #1
Federal Way, WA 98003
838-0842

Wheelchairs Northwest

1600 124th Ave NE, Suite A
Bellevue, WA 98005
646-4601 or 1-800-786-4508

7. Questions for Suppliers

- What kind of equipment and supplies are needed?
- If you don't provide both the durable medical equipment and the disposable supplies, who will coordinate the orders for the family?
- If you don't provide supplies, will you recommend a supply company?
- Are the families or the providers in charge of ordering and maintaining equipment and supplies?
- What kind of services are available on short notice?
- If there is a 24-hour response line, what does that mean is actually available? Technicians? Nurses? Delivery?
- Do you have experience working with pediatric patients and their families?
- Do you provide preventive maintenance on purchased or rented equipment?
- Since children may need new equipment, is there some arrangement for repurchasing used equipment when the child outgrows it?
- What is your agency's status with state and federal agencies, and with third party payers?
- Does your agency provide "loaners" or replacement equipment when equipment malfunctions?
- Does your agency furnish written instructions on equipment?

- Does your agency train home care personnel on the equipment?
- Does your agency keep track of the rate at which supplies are utilized, so that new supplies are ordered in a timely manner?
- If new supplies weren't ordered until the last minute, can you generally provide them on short notice? How short?
- Is information regarding whether and how supplies are to be cleaned and/or changed available in writing?
- In what conditions will supplies be stored? What arrangements can be made if storage is inadequate for more than a week's supplies?

For you to consider:

- Does your insurance company have preferred providers?
- Are your medicines also handled by the supply agency?

FINANCIAL RESOURCES

- **Emergency Resources**
- **Governmental Resources**
- **Home Modifications, Eyeglasses, and
Transportation Resources**
- **Insurance Guidelines and Helpful Insurance
Contacts**

1. Emergency Financial Resources

Alcohol/Drug 24-hour Helpline

722-3700 or 1-800-562-1240

Seattle

provides information and referral for assistance with alcohol and drug problems.

Community Information Line

461-3200

Seattle

provides information for a variety of needs, such as emergency housing, community supports, and mental health.

Domestic Violence Hotline

1-800-562-6025

provides information and referral for women and families involved in domestic violence for housing, financial, legal, and emotional assistance.

Food Banks

545-6600

Seattle

provides location and hours of operation of community food banks.

Local Churches and Synagogues

(see telephone directory)

may have emergency resources for people living in their area and not require church affiliation; Love Inc (Seattle 243-9463) is a clearinghouse for services offered through churches in south King County.

Multi-Service Centers

North and East King County (Bothell)

869-6000

South King County (Des Moines)

838-6810

offer a range of services including emergency family shelters, emergency food, motel vouchers, one-time assistance with heating bills, rent assistance, transportation, and more.

Salvation Army Social Services

447-9944

Seattle

provides food vouchers, rent assistance, assistance for water, light, and gas bills.

Society of St. Vincent de Paul

767-9975

Seattle

provides assistance with food, utilities, rent, and furniture.

2. Governmental Financial Resources

Federal Supplemental Security Income (SSI) Program

1-800-772-1213

(or contact your local Social Security Office in person)

Description:

SSI is a federal program that pays monthly checks to people who:

- are aged, disabled, and/or blind
- have limited income and assets

Payment may be made to children:

- who are disabled and if the physical or mental impairment is comparable in severity to one that would prevent an adult from working
- and whose disability is expected to last at least 12 months or result in death

Children who are eligible for SSI also qualify for Medicaid. Once an award letter has been received, parents need to take this letter to the local Washington State Department of Social and Health Services office to apply for Medicaid.

Washington State Department of Social and Health Services (DSHS)

Assistance through DSHS Economic and Medical Field Services (EMFS). To find the nearest EMFS office near you, call Seattle 298-4400.

Description:

1. Income Assistance:

- a. Aid to Families with Dependent Children (AFDC) provides financial assistance and medical coverage to eligible children and their caregiver-relatives. Eligibility is determined by income and resources;
- b. Family Independence Program (FIP) assists eligible persons in self-sufficiency through programs such as job development, work programs, employment, training, education, family planning, and child care. Eligible persons must be single parent or unemployed;
- c. Other financial services such as emergency assistance, refugee assistance, alcoholism and drug treatment, and aid to pregnant women.

2. Medical Assistance: payment for medical services (preventive care, doctor and dental visits, hospital care, glasses, hearing aids, prescriptions) and equipment for individuals receiving financial grants and those who meet income and resource requirements. Since July, 1994, many more children up to age 19 are eligible for health insurance through Medicaid. To apply for children's Medicaid, call 1-800-562-3022 and request the one-page application.
3. Food Stamps: eligibility is determined by income and resources.
4. Social Services: can include day care assistance for low income working parents, employment opportunities, refugee assistance and prenatal care.

Applying for assistance: bring identification, social security cards, proof of residence (lease, utility bill), documentation of all resources (bank statements, insurance, car registration), verification of income, and a list of expenses. It is important to bring proof of these expenses.

Assistance through DSHS Division of Developmental Disabilities (DDD) Seattle 720-3300 or (intake) 720-3322

Description: assists individuals of all ages with developmental disabilities to obtain a variety of services and supports. Eligibility is not based on income or resources, but funding is limited and needed services may not always be attainable. Services for children with developmental delays/disabilities include:

1. Child Development Programs: infant stimulation and therapies for children birth to three years of age;
2. Family Support Services: respite care, attendant care, in-home nursing care, and other inhome supports not available elsewhere or through other means;
3. Behavior Management Consultation and Intervention: technical assistance for caregivers in addressing difficult behaviors.
4. Case Management: assistance in identifying needs and resources, coordination of services, and advocacy.

Children with Special Health Care Needs through the Seattle-King County Department of Public Health Seattle 296-4610

Children with Special Health Care Needs (CSHCN) is a program to help provide linkage to necessary diagnostic, treatment, and other medical services or equipment for children under the age of 18 with special health care needs/disabling or potentially disabling conditions. CSHCN may

fund services when there is no other resource. Public Health Nurses and Family Resources Coordinators can provide case management/family resource coordination for the child (and family) with special health care needs without regard to financial resources.

3. Assistance with Home Modifications

Easter Seals Society

281-5700

Seattle

provides access modifications for people with disabilities; may install ramps, grab-bars, wide doorways, curb-cuts, special hardware, and handrails; provides information on how to remodel. Requirements: family must rent, be low income, and live in King County except Bellevue, Auburn, and Yarrow Point.

King County Housing Rehabilitation

296-7640

Seattle

low interest loans that help low or moderate income King County homeowners make improvements in their homes.

Labor Agency

448-9277

Seattle

retired carpenters provide some assistance with building ramps and putting in grab-bars.

Local Churches/Synagogues

(see telephone directory)

some families have mobilized church/synagogue members to assist in remodeling homes. Love Inc (Seattle 243-9463) is a clearinghouse for services offered by churches in South King County.

Seattle Housing Authority Housing Rehabilitation/REACH Program

684-0355

Seattle

or 443-4441

low interest loans that help low or moderate income people who live within the Seattle City limits make improvements in their homes.

4. Assistance with Eyeglasses

Lions Club District 19-B

363-3314

Seattle

assists with funding for eyeglasses and hearing aids (the above is a volunteer's telephone number).

5. Assistance with Transportation

Department of Social and Health Services (DSHS)

Medical Transportation Broker: 1-800-923-7433

Van Go: 1-800-201-8888

King County

DSHS provides funding for transportation to and from health care appointments for those on Medicaid, who have no appropriate means of transportation; "appropriate" transportation may include "cabulance" for those who are non-mobile or in wheelchairs; call at least 24 hours in advance.

6. Some Helpful Insurance Guidelines

Guidelines for Working with Insurance Companies

- Get a copy of your policy and read it carefully.
- Whatever is specifically listed as an exclusion is usually non-negotiable.
- All appeals must be in writing; all denials must be in writing; the longest a review can take is 30 days.
- The key is extensive documentation, defining why services are needed and having the doctor's approval for such services.
- Be assertive when dealing with insurance companies; write down the name of the insurance person you are communicating with and contact the same person when you need additional information.
- Based on the diagnosis of neurodevelopmental problems, children birth to six years of age in Washington State cannot be denied benefits, such as therapies; contact the Washington State Insurance Commission (Seattle 464-6262 or 1-800-562-6900) for further information.
- Pre-existing conditions are frequently not covered for a period of time; when switching insurance companies, make sure you check whether pre-existing conditions are covered.
- Most HMOs (Health Maintenance Organizations) and PPOs (Preferred Provider Organizations) are less restrictive about pre-existing conditions.

- During open periods of enrollment attend your employer's health fair and come prepared with specific questions about your needs, coverage, and concerns.
- Your employer is able to make changes in coverage during open enrollment; you may lobby your employer to encourage them to make changes in the insurance contracts.
- When your employer is contemplating changing insurance coverage, talk with your employer about what the change would mean for your child's coverage (pre-existing conditions).

7. Some Helpful Insurance Contacts

Washington State Insurance Commission
Seattle

**464-6262 or
1-800-562-6900**

may be able to provide some assistance regarding insurance coverage; mandates major policy changes

Washington State Health Insurance Pool

1-800-228-4044

provides health coverage for individual families who meet financial and age requirements

Washington State Basic Health Plan

1-800-529-7639

affordable health coverage for individual families who meet their financial and age requirements

Some of the above recommendations were obtained with permission from an information sheet prepared by the Kindering Center Father's Program in Bellevue

CHILD CARE

- **Finding Child Care**
- **What Is Respite Care?**
- **Child Care Checklist**
- **Children with Diagnosed Special Needs in Child Care**

1. Finding Child Care

We will call all kinds of care for you child "child care" whether it be day care, respite care, or babysitting. Parents need child care for different reasons, but the strategies for finding the right person to provide the care can be the same.

I. **How to get started: Finding the names of possible child care providers.** (These ideas are not in order of priority, and are just ideas--you may be able to find other resources.)

1. Family
2. Friends/neighbors
3. Churches or other social organizations
4. Home health care companies
5. Colleges, community colleges or vocational schools (especially nursing, occupational therapy/physical therapy, education, psychology, etc.)
6. Place ads in local or neighborhood newspapers, or post signs in public places (for example, churches, grocery stores, community centers)--be sure to state your expectations or needs in a positive way.
7. Other people/agencies who may be able to assist you in finding child care:
 - a. Yellow pages of your telephone directory under "Child Care" or "Nanny Services"
 - b. Child Care Resources (Seattle 461-3207, Bellevue 865-9350, Kent 852-3080)
 - c. Hospital social worker
 - d. Public Health Nurses (Seattle-King County Department of Public Health, 296-4600)
 - e. Family Resources Coordinators (KidCare, 284-0331 or 1-800-756-5437)
 - f. Children with Special Health Care Needs program (296-4610)
 - g. Case workers and case managers from DSHS Division of Children and Family Services (DCFS) or Division of Developmental Disabilities (DDD)
 - h. Programs that specialize in serving children with special development or health care needs:
 - Ashley House for children with complex medical care needs, Enumclaw, 825-6525
 - Exceptional Children's Center, Renton, 271-5330

- Kinderling Center, Bellevue, 747-4004
- Northwest Center Child Development Program, Seattle, 286-2322
- Northwest's Child Daycare (Darcy Hupf), Seattle 526-2493
- Special Sitters, Camp Fire Boys and Girls, Seattle 461-8550, Ext. 42

II. Now you have some names and numbers: *What next?*

1. **Screening:** call and ask for general information regarding services. Be prepared to tell them the age of your child and the hours or days that care is needed. You will want to ask if there are openings or a waiting list, the ratio of adults to children, fees charged, etc. (Please see the Child Care Checklist included in this packet.)
2. **Interview:** what should I say about my child? If the situation sounds acceptable to you, then discuss your child's special needs with the program director or person in charge. (Please see "Children with Diagnosed Special Needs in Child Care" included in this packet.) Be prepared to tell them specifically what kind of care your child will need that may be different from that for any other child. Be positive and clear. Don't forget to use lay people's terms.
3. **Tour:** if the provider seems positive, make an appointment to visit, and take your child with you. Take along the enclosed checklists for tips on what things to look for and what questions to ask.

III. You have found a provider! How to help make it a good experience for you and your child:

1. Take time to orient your child and his or her caregivers to a new situation.
2. Offer to show the caregivers how you do things. You can also arrange for people who may be working with your child to provide training (for example, Public Health Nurses, teachers, therapists, etc.). Remember that if the staff changes, you may have to train again.
3. Keep communication open. Check in regularly with your child's caregiver to see if there are any questions. Be sure to ask questions that you have. If you can't talk in person, consider writing notes or arranging regular telephone contacts.
4. Let staff know that you appreciate their support. Offer them information that you have. Many people want to help children with special needs--they just need to learn how!

IV. If you have concerns about your child's development (for example, hearing, vision, feeding, motor skill and/or play skills, language, etc.), here are some people who might be able to answer your questions or point you in the right direction:

- your doctor or pediatric nurse
- public health nurse
- local school district
- child development program (see "Family Resources" section)

2. What Is Respite Care?

Why Would I Use It?

How Do I Get It?

Respite Care may be a new word for parents. Some parents ask "Why do my friends use baby-sitter and they tell me to use 'respite'?" Respite care is help for parents with children who have special needs. It is help when there is less family support in the community for a child's care needs.

How do you spell relief? **R-E-S-P-I-T-E**

Relaxation: to relax and be more humorous

Enjoyment: in new activities

Stability: in face of crisis issues and maintaining the usual

Preservation: of the family unit; prevent abuse, divorce, neglect, exhaustion

Involvement: in community activities; less social isolation

Time off: alone or on a vacation

Enrichment: of your own identities

Ideas for getting respite care (hint: there aren't always programs set up or enough money to go around no matter how much your health care professional wants to get you and your family some respite)

1. Members of your church, family employers, neighbors, relatives. These people are familiar with your family, probably willing to help, but don't know what to do for you and your family. These people can be helpful by bringing food by for your family during especially difficult times for you or running errands you are too busy to do. They can babysit any of your children or be a mother's helper even when you are home. And respite can be skilled nursing care for part or all of the day.

2. Talk with your doctor, sometimes you can look at home health care on a short term basis for relief needed. Find out what other states or cities do for respite care and see if it can work for you.
3. Call your case manager with the Division of Developmental Disabilities to help identify possible funding sources for respite care services.

3. Child Care Checklist

This checklist is designed to help you make informed decisions about the child care programs you visit. You may change questions, or add questions you want to be sure to ask. Be sure you get all of your questions answered by the caregiver or by your own observations.

Good quality child care can be described as programs that have:

1. Caregivers who build children's self-esteem through warm, loving guidance, and who have training and experience in early childhood education.
2. A safe, comfortable and healthy setting.
3. Small child-to-staff ratio and group sizes.
4. Planned activities and environments that help children grow and learn mentally, physically, emotionally and socially.

The most important aspect is, of course, the caregiver. The personality, skills, training and child-caring philosophies of the people caring for your child are the major determinants of the kinds of experiences she or he will have each day.

CHOOSING CHILD CARE CHECK LIST

What Will My Child Do All Day?

1. Are there enough materials? Are they varied and within my child's reach?
2. Do the children in the program seem happy and relaxed?
3. Are there daily planned activities?
4. Will TV watching be limited?
5. Are there special activities geared to the needs of school-aged children?
6. Are there indoor and outdoor activities?
7. Are there field trips?
8. Will my child have fun?

9. Are quiet and active play planned?
10. Is the environment appealing and comfortable?
11. Are the toys age-appropriate and within reach of children?

How Will You Protect My Child's Safety?

1. Are there enough caregivers to give attention to all the children in care?
2. Are the toys and equipment safe and in good repair?
3. Is there a staff person present at all times who knows CPR and first aid?
4. Does the caregiver have accident and liability insurance?
5. Are there emergency procedures?
6. Are fire drills held monthly?
7. Is the outdoor play area safe and fenced, where needed?
8. Are there enough clear exits?
9. Have the caregivers had character reference checks?
10. Do I feel secure with the person(s) who will be caring for my child?
11. If my child is school-age, is there a plan for getting him/her to and from school safely?

How Will You Promote My Child's Health?

1. Are there guidelines regarding illness?
2. Is there space to isolate a sick child?
3. Are all areas clean?
4. Are efforts made to limit illnesses from spreading?
5. Do caregivers wash hands after diaper changes, blowing noses, and before food handling?
6. Are there health, nutrition and personal safety education programs?
7. Are medications handled in a safe way?
8. Are diapers changed often enough?
9. Are nap times and space planned?
10. Are arrangements made for those who don't wish a nap?
11. Are vehicles safe, insured, with seat belts?

What Will You Discipline For, and How Will You Do It?

1. Are limits reasonable, clear, and consistent?
2. Are hitting, biting and bullying dealt with appropriately?
3. Are teasing, shaming, scolding and shouting avoided?
4. Is positive reinforcement used?
5. Do the discipline policies match mine?
6. Do they avoid use of spanking or physical punishment?

What Will You Feed My Child and When?

1. Is there a weekly menu plan posted?
2. Is food balanced, varied and nutritious?
3. Are snacks nutritious and low in sugar?
4. Are children's food choices and appetites respected?

What Will You Do To Help My Child Feel Good About Him/Herself?

1. Does the caregiver smile, look at and talk with individual children?
2. Does the caregiver listen to individual children?
3. Is the caregiver warm and relaxed with a sense of humor?
4. Will my family's cultural values be respected?
5. Do caregivers focus on the positive behavior?
6. Does the caregiver encourage creativity and independence?
7. Do caregivers hold and rock infants and toddlers often?
8. Will the same people take care of my child each day?

How Will the Caregivers Be Supported?

1. Are training and education offered?
2. Are there sufficient substitutes on call?
3. Do caregivers take good care of themselves?

Will You Involve and Support Me as a Parent?

1. Am I free to visit at any time?
2. Are there parent conferences, meetings or workshops?
3. Is there a way for me to know what's happening on a regular basis?
4. Is there a written statement of policy and philosophy?

Other Things to Check Out

1. Ask to see the State License
2. Find out what kind of accident and liability insurance the program has.
3. Ask for the names and phone numbers of three parents in the program that you can call as references.
4. If it's a Child Care Center, ask if they have been or are in the process of being voluntarily accredited by the National Association for the Education of Young Children.
5. Ask how they prevent unauthorized persons from picking up children.

You'll know the experience is good if:

1. Your child is eager to go there each day.
2. Your child is happy when you arrive; even reluctant to go home.
3. Your child brings home a variety of things to show you.
4. Your child talks positively about friends, activities and the caregiver.
5. You notice the environment is kept orderly and interesting for children.

Adapted from Choosing Child Care, A Consumer Guide for Parents developed by City of Seattle Department of Human Resources and Washington State Department of Social & Health Services, Children, Youth & Family Services.

4. Children with Diagnosed Special Needs in Child Care

Many child care providers have successfully cared for children with diagnosed special needs in child care settings. "Children with special needs" includes children who may have a handicapping condition, who are developmentally delayed, or have unique physical, emotional, or mental conditions or needs. Serving such children can be a rewarding experience. It can reinvigorate teachers, sharpen awareness of normal growth and development, provide focus for putting a diversity curriculum into practice, and be an inspirational experience for all. However, it can take a little extra time and planning to successfully provide for children with special needs in your child care.

First, gather information from the parents. The following sample questions may help you to interview a prospective parent, to determine if the child's needs can be accommodated at your center:

1. What is the specific nature of the child's special needs?
2. Can the parents, or the child's physician or specialist, provide the following information:
 - a. Is the child already receiving adequate therapy, medication, and/or treatment? Who is providing these things? Will the child care need help with treatment? What kind of coordination may be necessary between the therapeutic regimen and yourselves as child care providers?
 - b. Are there any special techniques required for communicating with the child? If so, can therapists train the child care staff to use them?
 - c. Are there any diet/nutrition/feeding methods or needs that are unique for this child?
 - d. Are there any special symptoms, such as seizures, allergies, or breathing problems, that will require special attention/response?

- e. Are there any special physical or behavior management techniques being used with the child? How will child care staff communicate with other professionals involved so as to stay current on these techniques?
 - f. Are any specialized equipment or supplies necessary? Who will provide these?
 - g. Are there any limitations or accommodations for the child's activity?
 - h. How are emergencies handled?
3. Can the child's needs be met within the child care's present staff-child ratio? If not, are funding or assistance available to increase the ratio?
 4. Is the child care environment set up to accommodate the child's needs and any equipment, such as a wheelchair? Can it be modified within the child care's budget?
 5. Will the child care staff require any special training? What training resources are available? Consider parents, therapists, and the public health department, among others. Can these resources assist with helping staff, other parents, and the other children provide a positive entry for the child with special needs, and maintain a supportive atmosphere?

Once you have clearly identified the child's needs, and your needs for help, consider what resources are available to help you solve any issues. Are the parents knowledgeable about services and programs that are available to assist you? If not, look for resources on your own.

Some options may be to have the child care providers visit the current site where the child's therapy is in progress to observe the therapists at work with the child; have your staff attend care conferences at facilities serving the child, and/or have the current therapists provide some inservice training for the child care staff. Call your public health department to see what they offer. Or try calling an agency in your area which serves children with special needs, and ask for help.

After gathering the above information, the child care director should privately consider whether the staff and the other parents will welcome the challenge of the child with special needs. The director needs to provide the staff with adequate support to do this job well.

Once you have a child with special needs in your child care, sometimes concerns do arise. Document your concerns and observations, discuss them with the parents, and find an appropriate course of action. Parents are often the case managers for their children, and provide much of the coordination among services. And, of course, they are often the greatest source of information and support.

Printed with edits by permission from Child Care Health Handbook, available from the Seattle-King County Department of Public Health, 110 Prefontaine Place South, Suite 500, Seattle, WA 98104

FAMILY RESOURCES

- **Resources for Parents of Children with Disabilities:**
 - **Public**
 - **Medical**
 - **Educational**
 - **Support**
 - **Information**
 - **Peer**
 - **Special**
 - **Magazines**
- **Book List for Families**

1. Resources for Parents of Children with Disabilities

Parents of children with disabilities often seek information and support from other parents who share a common experience. This contact serves to share information about services and resources, brainstorm and problem-solve, receive and give emotional support and join together to create new programs and services.

Parent support groups may be sponsored by agencies serving persons with disabilities or may be started by parents in the community. Some focus on information sharing and others emphasize emotional support, or some do both.

Enclosed are resources that will assist family members in finding information, support, and intervention. Their functions vary and some new support groups may develop as others are discontinued. For updated information about resources, you may contact the ARC of King County (Seattle 364-6337), Community Information Line (Seattle 461-3200), or Children's Hospital Resource Line (Seattle 526-2500).

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5. Information Services, pages 5-9 and 5-10
6. Family/Peer Support Groups, pages 5-11 and 5-12
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1. Public Resources

Children with Special Health Care Needs

296-4610

Seattle

Seattle-King County Department of Public Health

Assistance with family resources coordination and funding of treatment services, equipment

Family Resources Coordinators

KidCare/Community Health Access Program

284-0331 or 1-800-756-5437

Provides help to identify concerns, priorities and resources related to your infant or toddlers developmental needs

Washington State Department of Services for the Blind **721-4410**
 Seattle

Assistance with a variety of services and programs for people with blindness

Washington State DSHS Division of Children and Family Services - Region 4 **721-4115**
 Seattle **(24 hours)**

Assistance with child protective services, day care, and foster home placement

Washington State DSHS Division of Developmental Disabilities - Region 4 **720-3300**
 Seattle **(Intake 720-3322)**

Point of entry for all state services for people with developmental disabilities

2. Medical Resources/Special Services for Children with Special Health Care Needs

Center on Human Development & Disabilities (CHDD) formerly CDMRC **545-1242**
 Seattle

Children's Hospital and Medical Center **526-2000**
 Seattle

Evergreen Hospital Medical Center **899-5555**
 Kirkland

Family child care team

Group Health, Capitol Hill **326-3000**
 Seattle

Seattle-King County Health Department

Auburn	833-8400
Central Area Health Center	296-2770
Columbia Health	296-4650
Downtown	296-4755
Eastgate	296-4920
Federal Way	838-4557
North Seattle	296-4765
Northshore	296-9814
Renton	296-4700
White Center	296-4646

Swedish Medical Center Seattle	386-6000
Valley Medical Center Renton	228-3450
University of Washington Medical Center Seattle	548-3300
Virginia Mason Tender Loving Care Seattle <i>Daycare for sick children</i>	583-6521

3. Education/Child Development Programs and Therapy Services

Birth to Three Developmental Center Federal Way	874-5445
Boyer Children's Clinic Seattle	325-8477
Children's Services of Sno-Valley Snoqualmie	888-2777 or 392-3762
Children's Therapy Center of Kent Kent	854-5660
Experimental Education Unit Infant and Toddler Program, University of Washington Seattle	543-4011, Ext. 108/109
Hearing, Speech & Deafness Center, Parent-Infant Program Seattle	323-5770
Highline Cooperative Developmental Center SeaTac	433-2579
Kindering Center (formerly Merrywood) Bellevue	747-4004

KWIAT Child Development Center Seattle	781-7655
Muckleshoot Birth-to-Three Program Auburn	931-6709
Northwest Center Child Development Program Seattle	286-2322
Puget Sound Educational Service District Seattle <i>Also contact your local school district's special services office</i>	439-3636
Valley Medical Center Children's Therapy Unit Renton	575-4715
Wonderland Developmental Center Seattle	546-8416

4. Information, Support, and Advocacy Organizations

The Arc of King County Seattle Newsletter - "Advocates" <i>information resource; information and supportive counseling for parents of children with special needs</i>	364-4645
American Cancer Society, Childhood Cancer Foundation 1312 18th Street NW, Suite 200 Washington, D.C. 20036 Newsletter - "Candlelighters"	(202) 659-5136 1-800-366-CCCF
American Juvenile Arthritis Organization Seattle	622-1378
Association for the Care of Children's Health (ACCH) 7910 Woodmont Avenue, Suite 300 Bethesda, MD 20814 <i>a multi-disciplinary international organization which promotes the psychological well-being of children and families in health care settings</i>	(301) 654-6549

The Association for Persons with Severe Handicaps (TASH) Seattle <i>organization that aims at supporting and disseminating information on aspects of the education of people who have severe handicaps</i>	523-8446
Autism Society of Washington South King County Chapter, Mary Ann Baker North King County Chapter, Ruth Gimpel Other Chapters (Seattle), Frances Dyer Newsletter - "The Diary"	432-9798 525-5678 368-0997
Bridge Ministries for Disability Concerns Redmond	882-0223
CAPP, Collaboration Among Parents and Health Professionals National Parent Resource Center Tacoma, Athena Elrod-Hovland <i>assists families on issues relating to health care services for their children with special health needs</i>	588-1741
Children's Resource Center, Children's Hospital and Medical Center Seattle <i>information resource</i>	526-2201
The Compassionate Friends, Grief Support for Bereaved Parents Seattle <i>newsletter</i>	241-1139
The Down Syndrome Community Renton <i>advocacy, support and community education</i>	228-2385
Easter Seal Society of Washington Seattle <i>comprehensive information, referral and advocacy for children and adults with disabilities; helps with housing, equipment, disabled parking privileges; has summer camps</i>	281-5700 or 1-800-678-5708
Epilepsy Association of Western Washington Seattle Newsletter - "The Open Door"	286-4440

Family Resources Coordination**284-0331 or 1-800-756-5437**

Seattle - KidCare

*assistance/advocacy for families of children birth to three with or at risk of developmental delay***Family Voices****(505) 867-2368****Internet: famvOlr@wonder.em.cdc.gov***a national grassroots network of families and friends speaking on behalf of children with special health care needs***Federation for Children with Special Needs****(617) 482-2915**

312 Stuart Street, 2nd Floor

Boston, MA 02116

"Fragile X" Association of Washington**(206) 629-4195 or 525-6525**

P.O. Box 15887

Seattle, WA 98115

International Rett's Syndrome Association (IRSA)**Phone #?**

Kathy Hunter

8511 Rose Lee Drive

Ft. Washington, MD 20744

Learning Disabilities Association of Washington**882-0792**

Kirkland/Redmond

Newsletter - *"The Missing Piece"***National Fathers' Network and Washington State Fathers' Network 747-4004 & 284-2859**

James May

16120 N.E. 8th Street

Bellevue, WA 98008

*personal support and advocacy for fathers of children with special needs; newsletter, annual conference, support and mentoring programs***Northwest International Rett's Syndrome Association (NIRSA)****487-9317**

Jeff and Mary Schaub

Bothell

Northwest Rett's Syndrome Foundation**(503) 657-3764**

Cindy Billups

13214 S. Warnock Rd.

Oregon City, OR 97045

PAVE, Parents Are Vital in Education	565-2266 or 1-800-572-7368
6316 12th Street	
Tacoma, WA 98465	
Newsletter - "PAVE Pipeline"	
<i>assists parents in advocating for their children's education</i>	
Parents of Prematures	283-7466
Seattle	
<i>newsletter, one-to-one support, monthly support groups, lending library</i>	
Parent-to-Parent Support	
Seattle	364-4645
Tacoma	588-1741
<i>provides opportunity for parents of children newly diagnosed with developmental disabilities to contact another parent with a disabled child</i>	
Community Health Access Program/Kid Care	284-0331 or 1-800-756-KIDS
Seattle	
<i>assists families in locating and accessing medical and other resources</i>	
Prader-Willi Syndrome Association	285-7679
Seattle, Susan Lundh	
<i>quarterly meetings and newsletter</i>	
S.O.F.T., Support Organization for Trisomy 18, 13 and Related Disorders	461-7834
Seattle, Debbie Samson	
South King County Family Resource and Support Group	854-6027
Kent, Charlene Monuszko	
<i>opportunity to connect with other families that include a member with a special need</i>	
South Seattle Parent Association	241-0838
Joy Cowell (evenings)	
<i>wide range of disabilities represented</i>	
Special Education Parent Advisory Council News	772-6934 or 1-800-422-GOAL
Washington State Parent Educator Partnership Project (WSPEP)	
12320 80th Avenue South	
Seattle, WA 98178	
Newsletter - "Pep Rally"	
<i>an organization for parents and professionals that promotes support and information regarding issues in special education</i>	

Tourette Syndrome Association 271-7296
20430 SE 119th
Issaquah, WA 98027

Turner Syndrome Society 363-3108
Seattle, Donna Eggen

United Ostomy Association 525-4403525-4403
Seattle
Newsletter - "*The Ostomist*"
meets 2nd Tuesday each month at Fred Hutchinson Center

Washington Coalition of Citizens with DisABILITIES (WCCD) 461-4550
3530 Stone Way North
Seattle, WA 98103
Newsletter - "Coalition Connection"
*supports people with disabilities who are seeking employment and helps organizations
comply with government regulations regarding disabilities and employment*

Washington State Commission for Children with Deaf-Blindness 439-6937
Seattle
services for families of children with deaf-blindness

Washington State Society for Deaf Children 771-4057
Halls Lake, Gina Pitts

5. Information Services

Child Care Resources
Seattle 461-3207
Bellevue 865-9350
Kent 852-3080
assists in finding child care and respite information

Children's Hospital and Medical Center
4800 Sandpoint Way NE
P.O. Box C-5371
Seattle, WA 98105
Children's Resource Center 526-2201
Resource Line 526-2500
*general newsletter from the Children's Resource Center regarding children's issues -
"Good Growing"*

- Community Information Line** **461-3200**
 Seattle
information and referral
- Head Injury Foundation, Washington State** **451-0000**
 Bellevue
 Newsletter
- National Association for Down Syndrome** **(708) 325-9112**
 P.O. Box 4542
 Oakbrook, IL 60521
 Newsletter
- National Down Syndrome Society** **(212) 764-3070**
 70 West 40th Street **1-800-221-4602**
 New York, NY 10018
- National Information Center for Children & Youth with Handicaps**
(NICHCY) **(703) 893-6061 or 1-800-695-0285**
 P.O. Box 1492
 Washington, D.C. 20013
 Newsletter - "*NICHCY News Digest*"
provides information to assist parents, educators, caregivers, and advocates to help children and youth with disabilities to become participating members of the community
- National Tuberous Sclerosis Association, Inc.** **(541) 346-2610**
 16944 125th Place SE
 Renton, WA 98055
- Pacific Northwest Regional Genetics Group, "Genetics Northwest"** **(503) 279-8342**
 The Oregon Health Sciences University
 Child Development & Rehabilitation Center/Clinical Services Bldg.
 901 East 18th Ave.
 Eugene, OR 97403-5254
provides information and education about genetics to patients, health professionals and educators
- Community Health Access Programs/Kid Care** **Seattle 284-0331 or 1-800-756-KIDS**
assists families in locating and accessing medical and other services

6. Family/Peer Support Groups

Asthma Support Group, American Lung Association Seattle, Stephan	441-5100
Burien Area Attention Deficit Disorder Parent Support Group Seattle, Linda DiMaria	433-2870
C.H.A.D.D., "Children with Attention Deficit Disorder" Valley Medical Center Renton, Sheila Anderson Renton, Pam Puhak Snohomish Chapter, Halls Lake, Deanna Cunningham <i>parent support group for parents of children with attention deficit disorders</i>	255-1169 235-7067 745-6261
The Cleft Connection Seattle, Joni Strong <i>resource for families of children with cleft lip and/or palate</i>	296-4665
Congenital Heart Defects Support Group Seattle, Rexie Knott Seattle, Tome Boe	526-2015 526-2167
Craniofacial Parent Support Group, Treacher Collins Foundation Seattle, Connie Arney	622-5131
Down Syndrome Community Seattle, Dick & Amy Jahn <i>advocacy, parent support, community education</i>	228-2385
Exceptional Parents Support Group Bellevue <i>parents of children with disabilities, held at Kinderling Center in Bellevue</i>	747-4004
Family Resources Coordination KidCare/Community Health Access Program Seattle <i>assistance/advocacy for families of children birth to three with or at risk of developmental delay</i>	284-0331 or 1-800-756-5437
Liver Diseases, GI Dysfunctions, Hirschsprungs Support Group Seattle, Dr. Dennis Christie	526-2131

National Fathers' Network

Bellevue, James May

747-4004, ext. 218

Woodinville, Paul Blair

488-8891*a group of men learning and growing together through parenting a child with special needs; social events, meetings, speakers, potlucks, annual campout***Northwest Center for Attitudinal Healing****362-3897**

Seattle

*support groups for persons with serious illness or injuries; separate groups for parents, children, spouses and friends of the ill or injured person***Parents Anonymous****524-5977**

Seattle

*free self-help groups for parents who are overstressed in dealing with their children; provides emotional support and child care during parent groups***Parents of Children with Attention Deficit Hyperactive Disorder****486-9007**

Children's Eastside Clinic

Bothell, Bonnie Reddick

Parent-to-Parent Support

Seattle

364-4645

Tacoma

588-1741*provides opportunity for parents of children newly diagnosed with developmental disabilities to contact another parent with a disabled child***Parent Support Group for Spina Bifida****775-2542**

Halls Lake

Renal Support Group**526-2524**

Seattle, Karen Baughman

parent support group for parents of children with kidney disorders

7. Special Services

Ashley House**825-6525**

Enumclaw

provides respite care for children with medically intensive needs

Community Health Interpretation Service Seattle <i>foreign language interpreters</i>	324-7835
Community Service Center for the Deaf & Hard of Hearing Seattle <i>information and interpreter referral service</i>	322-4996
Community Support Project Seattle <i>technical assistance in behavioral management and crisis intervention</i>	286-4440
Evergreen Legal Services Seattle	464-5911
Family Resources Coordination Seattle <i>assistance/advocacy for families of children birth to three with or at risk of developmental delay</i>	284-0331 or 1-800-756-5437
Love Inc. Seattle, Katy Lynch <i>handicapped construction, maintenance, repair, transportation, counseling, etc.</i>	243-9463
Interpreting Services for Deaf or Limited English Speaking Seattle <i>Red Cross Language Bank, staffed by volunteers</i>	323-2345
Make-A-Wish Foundation Mercer Island, Terry Carstensen <i>grants wishes to children with terminal illnesses</i>	236-2133
"Mee Too" Clothes for Kids Box 710, Nelson, B.C., Canada V1L 5R4 <i>"a unique new line of adaptive clothing for young people that's fashionable, functional & fun to wear," from size 3 to 18</i>	(604) 352-9181
Retired Contractors Union Seattle, Jan <i>construction modifications; helps modify homes for wheelchair accessibility and other special needs</i>	448-9277

Specialized Programs of the Seattle Parks and Recreation Department

684-4950

Seattle, Nick Bicknell

provides year-round enriching recreation experiences for youth five years of age and older with limitations that may prohibit them from regular community recreation programs. Call your local parks and recreation department for details

Washington Protection and Advocacy System

324-1521

Seattle

seeks to ensure the civil rights of persons with mental illness or developmental disabilities

8. Magazines and Newsletters

CHARGE (or Pagon) Syndrome National Newsletter

2004 Parkade Boulevard

Columbia, MO 65202

"Charge Accounts"

"Exceptional Parent"

Box 3000, Dept. EP

Denville, NJ 07834

magazine for parents and educators who live and work with children with disabilities

National Fathers' Network Newsletter

16120 N.E. 8th Street

Bellevue, WA 98008

a twice-yearly newsletter entirely written by men parenting children with special needs

Sibling Information Network

(203) 282-7050

991 Main Street

East Hartford, CT 06108

Newsletter

an organization for those interested in the welfare of persons with disabilities and their families

9. Book List for Families of Children with Special Needs

There are many books for families of children with special needs. This list will serve as a start for you. Many books have other books listed at the end. We have listed books of general interest and those specific to a particular illness or disability. (The number at the end is the library number for your convenience.)

Washington State Parent-to-Parent Programs (364-4645) has compiled a collection of books of interest to families with children with special health care needs (the "Special Needs Collection" 1995) with the plan that more of these books will be available through your library system. The state library will be publishing a directory of library books related to children with special health care needs.

ONE MIRACLE AT A TIME: A GUIDE FOR PARENTS OF DISABLED CHILDREN.

Dickman, Irving. Simon & Schuster, 1985

"Many parents are still looking for the same book we couldn't find, a book about how things are, not how they're supposed to be" --the author's reason for this book. Topics include: getting a diagnosis, how other parents help, choosing doctors and therapists, getting early intervention aid, where to find financial help, and advocacy techniques. Written by parents for parents.

THE CHRONICALLY ILL CHILD: A GUIDE FOR PARENTS AND PROFESSIONALS.

McCollum, Audrey. Yale University Press, 1981. (362.19)

"How do parents feel when faced with the threat of serious illness or disability in their child? Is it helpful to know what others have experienced? Many parents believe it is. Knowing how others have felt in similar circumstances can reduce the sense of being utterly alone." This starts the book; chapters on facing the diagnosis, family relationships, and coping with each age group.

NOBODY'S PERFECT: LIVING AND GROWING WITH CHILDREN WHO HAVE SPECIAL NEEDS.

Miller, Nancy. Paul Brooks Publishing, 1994.

A DIFFERENCE IN THE FAMILY.

Featherstone, Helen. Penguin Books, 1982. (362.4043 FEA)

A mother's story of raising a severely disabled child. Much insight into family life and the effects of disability on it. Very helpful.

AFTER THE TEARS: PARENTS TALK ABOUT RAISING A CHILD WITH A DISABILITY.

Simons, Robin. Hartcourt Brace, 1987. (649.151 SIM)

In parenting a child with a disability you face a major choice. You can believe that your child's condition is a death blow to everything you've dreamed and worked toward until now. Or you can decide that you will continue to lead the life you'd planned - and incorporate your child into it." A tremendous book of short chapters on many subjects - stories of parents and lots of encouragement.

LIVING WITH A BROTHER OR SISTER WITH SPECIAL NEEDS.

Meyer, Donald, Vadasy, P. and Fewell, R. University of Washington Press, 1995. (Y362.4088 MEY)

Tells the effect of a child with a disability on the siblings, from their point of view and from their perception of the "problems" and rewards. Easy to read and use for any age of sibling.

SIBSHOPS: WORKSHOPS FOR SIBLINGS OF CHILDREN WITH SPECIAL NEEDS.

Meyer, Donald, Vodasy, Patricia. Paul Brooks Publishing, 1994.

PARENT RESOURCE DIRECTORY.

Association for the Care of Children's Health, 3rd Edition, January, 1989.

Compiled list of families from every state and Canadian provinces with children with disabilities. Cross-referenced into categories of disability and types of interest and advocacies the families do. Each family listed can be contacted by address or phone. An evaluation form is included at the end of the book.

BABIES WITH DOWN SYNDROME: A NEW PARENT'S GUIDE.

Edited by Helen Stray-Gundersen. Woodbine House, 1986. (616.353342)

Detailed and practical book on the background and present and future care of your child with Down Syndrome. Many pictures and stories to add to the reality of the written word. Highly respected book by families and professionals alike.

CHILDREN WITH CEREBRAL PALSY: A PARENT'S GUIDE.

Edited by Elaine Geralis Tomlinson. Woodbine House, 1989.

Same respected publisher for parent's book on caring for and learning about their child with cerebral palsy. Chapters on background and treatment and family coping. Good resource listing at the end of the book.

CHILDREN WITH EPILEPSY: A PARENT'S GUIDE.

Edited by Helen Reisner. Woodbine House, 1988.

Complete book on the needs of parents, families and children with epilepsy. Up to date and factual for parents who may have heard many different pieces of information. Each book by this publisher is complete with current information.

CHILDREN WITH ASTHMA: A MANUAL FOR PARENTS.

Plaut, Thomas, MD. Pedipress, 1988.

"When asthma is not well-controlled, it may severely disrupt the living patterns of the families affected by it. A child with undertreated asthma may experience an episode suddenly and with little warning, causing panic and upheaval in the family unprepared to respond. Can we improve the ability of parents and their children with asthma to manage asthma at home? The answer is a definite yes." Chapters on living with asthma, medical management, support groups, and many charts and pictures to make it all easy for parents.

TIME TO BEGIN - DOWN SYNDROME.

Dmitriva, Valentine. Caring, Inc., 1982.

Recommended by support groups of families with children with Down Syndrome as an informative and helpful book to deal with the disability and to inform.

FATHERS OF CHILDREN WITH SPECIAL NEEDS: NEW HORIZONS.

May, James. Association for the Care of Children's Health, 7910 Woodmont Ave., Bethesda, MD 20814; (301) 654-6549, 1991.

Discusses the impact of a child with chronic illness or developmental disability on fathers. Includes information on support programs, how professionals may include fathers in their medical and educational services.

SUPPORT PROGRAMS FOR FATHERS OF CHILDREN WITH SPECIAL NEEDS: CIRCLES OF CARE AND UNDERSTANDING.

May, James. Association for the Care of Children's Health, 7910 Woodmonth Ave., Bethesda, MD 20814; (301) 654-6549, 1991.

Discusses how parents and professionals may organize family-centered, community-based support programs for fathers and their families.

BROTHERS AND SISTERS (SIBLINGS)

- **On the One Hand...**
- **On the Other Hand...**
- **Parents' Job: Communication, Communication,
Communication**
- **Resources for Siblings**

On The One Hand ...

When you think of it, the sibling relationship is the longest lasting relationship in the family. In many cases, the same thing happens to siblings of persons with special needs that happens to parents--they do and become many wonderful things that they would not otherwise have done or become if they did not have such a person in their life.

They tend to be better adjusted, more responsible, and have greater maturity than their peers. They develop a great amount of patience and understanding by living with a person with special needs and in dealing with an ignorant or even prejudiced general public. They learn diplomacy by answering many questions and responding to many inquiries about their brother or sister. And they know what it means to give and to sacrifice.

Siblings tend to be less susceptible to peer pressure and to understand that it's okay to be different. They have a different and better value about people and life than many other people. They are oriented toward helping others and entering the helping professions. They have an ongoing quest for learning about disabilities and develop strong, real friendships based on a positive disregard of people's limitations. They have an optimistic perception of what their brother or sister can do and an appreciation of good health and family unity. And they develop a strong loyalty toward their sibling with special needs (even if they fight with him/her at home or in private!).

On The Other Hand ...

Brothers and sisters of persons with special needs can go through a variety of misunderstandings and emotions and feelings regarding their siblings. Unless these are understood and discussed openly, a very unhappy childhood and negative lifelong effects can occur among all involved.

Some of the emotions and feelings and misunderstandings are:

1. "Overidentification": thinking that "I'm going to be like that" or "I'll catch that."
2. Embarrassment: from "differentness," from stares, behavior in public, ridicule from peers and others.
3. Guilt: feeling responsible for the disability or for not having the disability ("survivor's guilt"); for getting angry at the sibling with special needs; for passing the sibling in abilities; and for leaving home when an adult.
4. Isolation: feeling alone by having a sibling incapable of sharing; feeling loneliness and the inability to share and discuss with anyone.

5. Resentment: when emotional and financial resources are directed toward the sibling with special needs; when the sibling is indulged, overprotected, allowed to get away with things, coddled and cuddled more, etc.
6. Defensiveness: feeling the need to defend the sibling at all costs; being angry at others because they don't understand or treat her/him in exactly the right way; feeling responsible to protect her/him.
7. Concerns about the future: how will the sibling be cared for when (s)he grows up; where will (s)he live; who will care for her or him when mom and dad are gone; what options are there for the future; who will be responsible for decisions concerning her/him.

It is important to note that embarrassment occurs mostly among siblings of the same sex. It is also important to know that oldest daughters of siblings with special needs are at highest risk of increased emotional problems, compulsion to achieve, and educational failure. This stems primarily from parents giving them, because of their age, more caregiver or surrogate-mother tasks and chores than younger children (oldest sons are often exempted from these tasks and chores).

Parents' Job: Communication, Communication, Communication

In reality, siblings' misunderstandings, feelings, and emotions do not differ much from those of their parents, except perhaps at a simpler level. It is important for parents to understand this and take the lead in communicating with their children at their level of understanding about their sibling's delay or disability. It is also important for parents to know that their children, like they themselves, need various kinds of support.

Some of the things that parents must provide for their children are:

1. Accurate information about the disability that is age appropriate, so that the children can understand it themselves as much as possible and be able to answer others' questions without shame or embarrassment.
2. Open discussion about feeling bad, sad, or mad about the disability and an invitation to the children to discuss their feelings and emotions, no matter how terrible they seem.
3. Peer support or opportunities for children to meet other siblings of children with special needs, so that they can share concerns and talk about various situations.
4. Special time and attention for children without special needs, so that they do not feel neglected or rejected because of their sibling.

5. Knowledge of sibling issues and problems by reading books and articles on the topic and by discussion with other parents, so that parents can be fully aware.
6. Realistic goals about what is expected of the children both with and without special needs in the areas of caregiving and care-receiving, education, athletics, etc.
7. Future plans of care/training for the child with special needs so that siblings are not left wondering and worrying.
8. Positive view/optimistic attitude about being parents of a child with special needs, so that the other children can share the same view and attitude as siblings.

Resources for Siblings

The following information is taken from Volume 10, Issue 10 (August 1991) of "Habilitation!" published by The Disabilities Research and Information Coalition (DRIC), 3530 Stone Way N, Seattle, WA 98103. This issue contains articles by or about brothers and sisters of children with special needs and is an excellent resource in itself.

The Sibling Support Project: This Seattle-based project developed the concept of "Sibshops," a low-key seminar that provides brothers and sisters of children with special needs an opportunity to meet other siblings in a relaxed recreational setting. For more information, call or write:

Donald Meyer, Sibling Support Project
Children's Hospital
4800 Sand Point Way NE
Seattle, Washington 98105
(206) 368-4912

Sibshops: For more information on existing sibling support groups in your area, write or call:

Elaine Schab-Bragg
The Arc of King County
10550 Lake City Wy NE, Suite A
Seattle, Washington 98125-7752
(206) 364-4645

Pearl Wollin
Providence Children's Center
P.O. Box 1067
Everett, Washington 98206
(206) 258-7311

Monica Burnham
Kent Parks & Recreation
315 E. Meeker Street
Kent, Washington 98031
(206) 859-7513

Susan Atkins
Parent to Parent
6140 Capitol Blvd. # 632
Olympia, Washington 98501
(206) 493-1885

Good Reading: Check out these two books for information on starting and participating in sibling support groups for children age 3 to 13:

Brothers, Sisters, and Special Needs by Deborah Lobato
(Paul Brookes Publishing, 1990)

Sibshops by Donald Meyer, Patricia Vadasy, Rebecca Fewell
(University of Washington Press, 1986)

TRANSITION FROM HOSPITAL TO SCHOOL

- **Educational and Developmental Services to
Children with Special Needs - an Overview**
- **Key Questions from Parents ...**
- **Transition Planning**
- **Resource List:
Washington State Public School System
Parent Education/Advocacy Groups**
- **School Information Packet Guidelines**

Prepared by:

The Educational Department at Children's Hospital and Medical Center

*March, 1992
(revised January, 1996)*

Educational and Developmental Services to Children with Special Needs - an Overview

Most hospitalized children and their families look forward to discharge from a medical setting. This represents an important point at which many of the health-care goals have been accomplished, and from the perspective of professionals and family members, the needs of the child are best met outside of the hospital setting. It is also a time when the family and community professionals will assume the major responsibility for the child's continued growth and development.

If your child is between the ages of 3 and 21 years ... and has difficulty in seeing, walking, hearing, communicating, learning or getting along with other children and adults, he/she may be a candidate for special education or early intervention services through your local school district.

Washington state and federal statutes (the Individuals with Disabilities Act, or IDEA) require that school districts identify all children between the ages of three and 21 years with disabilities that might interfere with normal learning and development, and provide an appropriate education at no cost to parent(s) or legal guardian.

You, or anyone else who is involved with caring for your child, such as a day care worker, health-care provider or teacher, can express your concerns through written or oral form to your local school district superintendent or his/her designee. This is called a Focus of Concern. The school district will then begin to gather information about the child's specific educational needs.

To be eligible for special or early intervention services, your child must have one or more disabilities recognized by federal and Washington state laws. These include preschool developmentally disabled, seriously behaviorally disabled, orthopedically impaired, specific learning disabled, mentally retarded, multidisabled, deaf, hard-of-hearing, visually disabled, deaf-blind, communications disordered and health impaired.

Second, your child's disability must significantly interfere with his or her normal development (preschool age) or ability to learn in a regular classroom environment, thus, requiring "special education and related services".

As part of the school's assessment process, a wide variety of specialists (multi disciplinary team) will evaluate all areas of your child's disability. Your child will be formally tested and observed in a variety of settings such as a classroom or your home. The team will then make recommendations regarding your child's needs for specialized materials or equipment, learning strategies and the special education and related services that your child needs to benefit from his or her educational placement.

All of these recommendations are summarized in an Individual Education Program (IEP). This is a written plan which is reviewed annually and describes your child's present levels of performance, annual goals and short-term objectives and the extent and types of services which will be offered during the school year. It also states where these services will be provided, the starting date and how long these services will be available.

Services for your child may be provided by a wide variety of specialists, including teachers, nurses, speech and language therapists, physical and occupational therapists, psychologists, social workers and recreational therapists. Your child's primary physician may also be involved to provide information on how your child's physical or health-related conditions might affect normal development and learning.

School districts must ensure that you are fully involved with the process of identification, evaluation and school placement of your child. They must obtain your written permission prior to conducting any evaluations and prior to making a decision about how and where your child will be served. You also have the right to challenge any school district decisions which affect your child's educational development.

If your child requires health care during the school day, it is essential that you contact the local school district to determine the availability of school health services. These services include vision, hearing or scoliosis screening, clean intermittent catheterization and administering medication among others. They are provided by a trained school nurse or other qualified person at no cost to the parent(s) or child, and they are generally prescribed and monitored by your primary health care provider. These services are available to all school-age children, including those with disabilities who do not qualify for special education services.

For health planning purposes, the following information about your child should be provided to your school district?

- diagnosis;
- special health procedures required to maintain the student in school;
- medication and dietary prescriptions;
- transportation requirements, including equipment, staff, communication and emergency procedures;
- equipment and/or materials needed daily and for emergencies;
- facility alterations or adaptations which may be required;
- training needs of each member of the service delivery team, including certified, classified, health and other staff to be involved;
- contingency and emergency plans;
- contact person(s) from the discharging medical facility who can provide additional information upon request;
- local primary care provider; and the extent and type of parent involvement;

Planning around these topics between you, hospital and local school district staff can prevent unreasonable expectations of school health services. Your primary care provider frequently is in the best position to assess how best to meet your child's health care needs within the school or developmental setting, and should be involved in this planning.

Remember ... Only the school district can determine if your child is eligible for special education and related services. If your child does not qualify for special education or related services, he or she is still entitled to reasonable accommodations within the school setting. Changes in buildings, interpreters for hearing impaired children who do not require special education, and assistive technology devices are some of the ways that your child's disability maybe accommodated.

If you have an infant or toddler between the ages of birth and 3 years who does not seem to be developing in the same way compared to other children in this age range ... he or she may need early intervention services. These services are designed to encourage normal developmental patterns and improve your child's overall functioning.

There are several key points to remember about early intervention services. First, because of your child's very young age, he or she is extremely dependent upon you for support, nurturance and gentle guidance toward normal developmental milestones. That means you are an important part of any service plan that is developed for your child. Your continuing involvement is likely to be the most important reason for your child's continuing development.

Second, very young children often have many different types of special needs. That means a wide variety of services may be offered to you and your child. These include vision and hearing tests, family training and counseling, occupational and physical therapy, psychological services, special education and speech and language therapy.

The early intervention services your infant or toddler will receive are described in an Individualized Family Service Plan (IFSP) that is reviewed upon your request or at least every six months.

In many ways, this written plan is similar to an IEP for a schoolage child. It must include your child's present levels of development, describe specific goals and objectives along with timelines for completion, the specific services that will be provided and for how long. It also must include a plan for how your infant or toddler will make the transition to special education services at age three, if these are likely to be necessary. Finally, the IFSP must specify what agencies and services will be most useful to you, as a parent, so that you can best meet the needs of your developing child.

A resource coordinator from a profession most directly related to your child's disability, including a nurse or even a physician, is responsible for seeing that your child's plan is working effectively in behalf of you and your child.

In King County, early intervention services are generally provided at developmental centers. However, for some children, early intervention services may also be provided in the home by a visiting therapist, at a therapy setting in a hospital, or as part of an evaluation process through a local clinic, hospital or public health agency.

Who's Eligible?

To be eligible for early intervention services your child must meet eligibility criteria for certain agencies in Washington state. These include the Division of Developmental Disabilities, public schools or Children with Special Health Care Needs (formerly called Coordinated Children's Services).

Second, as part of the referral and evaluation process, a multi disciplinary team must find that your child has a significant delay in any one or more of the following areas of development: cognition, language and speech, motor, social-emotional or self-help skills.

Your child may also receive services if he or she has a diagnosed physical or mental condition that is likely to cause developmental delay. If your child has mental retardation (for instance, Down syndrome), spina bifida, poor vision or hearing, cerebral palsy or other health and physical impairments, it is important to begin early intervention services as soon as possible. This could increase the chances that he or she will be able to spend as much time as possible in a regular classroom upon reaching schoolage.

Key Questions from Parents ...

What should I do if I don't think my child is meeting normal developmental milestones?

The best thing might be to contact your local primary care provider and share your concerns. If your child has a disability which is interfering with normal development and learning, you or your physician should contact a developmental center or public school program which is closest to you. Staff from these programs will set up a time for an evaluation and interview which is convenient for you and your child. A list of centers and school districts in King County is provided following this section.

If you do not have a primary care provider, or wish a second opinion, you can contact the KidCare/Community Health Access Programs of King County (284-0331, or 1-800-756-KIDS). This program can assist in referring your child for an evaluation, and help identify health care services for your child.

What special services are available in the schools for children with special health care needs?

Whether or not your child is receiving special education services, he or she is entitled to school health services to enable participation in a public school program. You should contact the special education office in your local school district and inquire about the availability of specific services which your child needs.

If your child has a health condition such as cancer, leukemia, attention deficit disorder or a traumatic brain injury, he or she may be eligible for special education under the category Health Impaired. Your physician will be asked to provide specific information about how your child's health condition might affect his or her educational performance. A description of your child's vision and hearing is also required. All of this information will assist the multi-disciplinary team in determining what types of services are appropriate for your child.

My child is often not feeling well and often misses school. What can I do to help?

Children with asthma, sickle cell anemia, cystic fibrosis, cancer or leukemia often don't feel well enough to attend a classroom program. These children are eligible for homebound instruction if they are likely to miss at least four or more weeks of school, either consecutively or intermittently during the school year. To receive this service, your child's physician must sign an application form which can be obtained from your child's local school program.

Sometimes I'm not sure that I understand everything there is to know about my child's school program. What's the best way to get help?

Of course, the best place to start is with your child's school team. A school nurse, school psychologist or teacher can often help you understand all the benefits and services your child is entitled to. Each school district usually has pamphlets or other written information about their school services. There are also community services designed to help parents determine if their child is receiving an appropriate educational program. These include Washington PAVE (Parent-to-Parent Training Project), the Washington State Parent/Educator partnership Project and the Education Law Project of the Washington State Special Education Coalition. A description of the services available from these agencies, and their telephone numbers and addresses are provided in the following section.

What can I do if I don't think my child is getting appropriate special education or early intervention services?

Washington state and federal laws guarantee that you, as a parent, have an opportunity to express your concerns about your child. In many cases, conflicts can be resolved by providing better information about your child's needs and seeing that all involved care givers are communicating with each other. This can be done through a variety of informal steps. For instance, you can ask for an IEP or IFSP meeting or send a letter to your local school district's special education director which explains your concerns.

You can also seek clarification on specific issues by calling one of the community agencies mentioned in the preceding paragraph. Or, you can request that your child be evaluated by someone outside of the school program.

More formal procedures are available to resolve differences between parents and school staff. You may request mediation, which is confidential, inexpensive and likely to lead to a solution acceptable to all parties. You may also ask for an opportunity to present your concerns to a hearing officer who cannot be an employee of the school district. Finally, if you feel that a school district is not following state and federal laws in serving your child, you can file a citizen's complaint. You should contact a parent organization and request assistance, however, before proceeding with any of these more formal ways of resolving differences between you and your local school district.

Transition Planning

Children with complex, health-related concerns require a coordinated, well-planned transition to local school agencies or developmental centers due to the involvement of multiple service providers, complex family needs or, for some children, a lengthy hospital admission. For these reasons, discharge planning for hospitalized children should begin upon admission, and is the collective responsibility of medical staff, community agencies and the family.

Washington state law allows up to 100 days for school districts to respond to a referral for evaluation, determine your child's eligibility for special education and related services, and decide where these services will be provided. Direct communication between you and your child's health care providers, and local school district staff is essential. Agreement about the type of information to be shared is likely to speed up any decisions on how and educational services will be available for your child.

Guidelines for Completing a School Information Packet are included at the end of this pamphlet. This can assist you in collecting information which might be useful for planning a school or early intervention program for your child.

Resource List

The public school system in Washington state operates at three levels. The Office of the Superintendent of Public Instruction (OSPI) and State Board of Education primarily establish rules and regulations in Washington state, and ensure the overall quality of school programs and their personnel. Educational Service Districts (ESDs) are regional bodies who act as an important link between local schools and OSPI. School districts are responsible for delivering services to children.

Children birth to three years may be served in public school programs, but in King County, services are provided through developmental centers.

Telephone numbers and addresses of programs in King County are provided below.

Washington State Public School System

Office of the Superintendent of

Public Instruction (OSPI)

Old Capitol Building

P.O. Box 47200

Olympia, WA 98504-7200

Special Education Phone: 753-6733

Auburn School District

915 4th St. N.E.

Auburn, WA 98002

Special Education Phone: 931-4927

Bellevue School District

12111 N.E. 1st St./P.O. Box 90010

Bellevue, WA 98009-9010

Student Services Phone: 455-6066

Enumclaw School District

2929 McDougall Ave.

Enumclaw, WA 98022

Special Services Phone: 825-6393

Federal Way School District

31405 18th Ave. So.

Federal Way, WA 98003

Special Education Phone: 941-0100/927-7420

Highline School District

15675 Ambaum Blvd. S.W./Box 66100

Seattle, WA 98166

*Special Education Phone: 433-2125
2421/2362*

Kent School District

12033 S.E. 256th

Kent, WA 98031-6643

Special Education Phone: 859-7511

Lake Washington School District

10903 N.E. 53rd/P.O. Box 2909

Kirkland, WA 98083

Special Services Phone: 828-3201

Puget Sound ESD

400 S.W. 152nd St.

Seattle, WA 98166-2209

Special Services Phone: 439-6916

*Early Childhood Education Phone:
439-6906*

Mercer Island School District

4160 86th Ave. S.E.

Mercer Island, WA 98040-4121

Student Services Phone: 236-3330

Northshore School District

18315 Bothell Way N.E.

Bothell, WA 98011-1983

Special Education Phone: 489-6000

Renton School District

435 Main Ave. So.

Renton, WA 98055

Special Programs/Svcs. Phone: 235-

Issaquah School District

565 N.W. Holly St./Box 7003

Issaquah, WA 98027-7003

*Special Services Phone: 392-0746
4611/788-6610*

Seattle School District

815 4th Ave. No.

Seattle, WA 98109

Special Education Phone: 298-7935

Shoreline School District

18560 1st Ave. N.E.

Seattle, WA 98155

Special Services Phone: 361-4213

Skykomish School District

Skykomish, WA 98288

Superintendent Phone: 677-2623/464-5460

Riverview School District

32240 N.E. 50th St.

Carnation, WA 98014

Special Education Phone: 333-

Snoqualmie Valley School District

P.O. Box 400

Snoqualmie, WA 98065

Special Services Phone: 888-2334

South Central School District

4640 So. 144th St.

Tukwila, WA 98168

Superintendent Phone: 248-7564

Tahoma School District

22015 S.E. 216th Way

Maple Valley, WA 98038-8412

Special Services Phone: 432-5757

Developmental Centers**Birth to Three Developmental Center**

Merrywood)

874-5445

Federal Way

Kindering Center (formerly

747-4004

Bellevue

Boyer Children's Clinic

325-8477

Seattle

KWIAT Child Development Center

781-7655

Seattle

**Children's Services of Sno-Valley
Program**

888-2777 or 392-3762

Snoqualmie

Muckleshoot Birth-to-Three

931-6709

Auburn

**Children's Therapy Center of Kent
Program**

854-5660

Kent

NW Center Child Development

286-2322

Seattle

**Experimental Education Unit Infant and District
Toddler Program, University of Washington**
Seattle
543-4011, Ext. 108/109

Puget Sound Educational Service

439-3636
Seattle

**Hearing, Speech & Deafness Center
Therapy**
Parent-Infant Program
323-5770
Seattle

Valley Medical Center Children's

Renton
575-4715

Highline Cooperative Developmental Center
433-2579
SeaTac

Wonderland Developmental Center
546-8416
Seattle

Parent Education/Advocacy Groups

**Washington State Parent/Educator
Project**
Partnership Project (WSPEPP)
400 S.W. 152nd St.
Seattle, WA 98166-2209
Phone: 439-3636

Washington State Education Law

217 9th Ave. No.
Seattle, WA 98109
Phone: 547-0200

Washington State PAVE
6316 So. 12th
Tacoma, WA 98465
Phone: (800) 5-PARENT

School Information Packet Guidelines

The following is a list of the topic areas that have been presented in past School Information Packets. Under each category are examples of the kinds of information that could be included, depending upon the child being discussed.

I. Medical Issues

Include any ongoing medical issues, e.g., seizures, surgeries planned, TLSO weaning; name of primary care M.D.

Medications: List meds, whether any will need to be given during school, if so who needs to give them and when; list potential side effects to alert school staff.

II. Sensory Functioning

Vision, hearing; functional implications of deficits in either area, e.g., ability to see blackboard, read, look rapidly from blackboard to desk, etc.

III. Mobility and Related Issues

Mobility: Indicate mode(s) of mobility on discharge - short and long distance, classroom, between classes, in crowds, stairs, supervision/assist required, need for "buddy system", need for helmet, need for extra time to move between classes.

School Accessibility Requirements: Rooms, ability to access equipment and supplies, need for ramps/elevators.

Pathfinding: Level of skill, cuing and supervision required: best methods for learning new routes.

Endurance: Physician endurance for full day of school; need for rest breaks.

ROM, Positioning, Transfers: ROM needed at school; positioning options for school, optimum positioning for various school activities; any type of transfer that might be needed in school setting (toilet, chair, floor, bed).

Equipment: What equipment is used, when, who monitors.

Outdoor Activities/Recess/PE/Playground: Physical restrictions, safety considerations, equipment needed, appropriateness of adaptive PE, supervision.

IV. Self-Care and Related Issues: Diet/Nutrition

Type of diet, need for assist, precautions, food selection, meal supervision, equipment, any restrictions.

Toileting: Level of continence, dependent/independent in indicating need to void, type and amount of assist needed, extra clothes required, special bathroom/changing set-up, what is required if incontinent, cath schedule and needs.

Dressing: As related to school needs, e.g., if incontinent.

V. Fine Motor/Upper Extremity Skills

Fine Motor Skills: Ability to perform basic fine motor skills; impact on school tasks such as cutting, writing; need for compensatory strategies or equipment; ROM required.

Handwriting and Written Expression: Level of skill motorically; level of skill in written language; copying and formulation abilities; need for extra time to complete writing; need for extra practice; recommendations for typing or computer use.

VI. Behavior/Adjustment

Concentration, Task Persistence, Attention: Ability to attend to different types of tasks; amount of cuing and redirection required; effect of environmental distractions.

Individual Work Skills, Ability to Work in Groups: Include best environment for school-related tasks.

Peer Relations:

Frustration Tolerance: What types of tasks are frustrating; what is the response; how should adults address this.

Awareness of Difficulties:

Inappropriate Behaviors:

Behavioral Management Techniques:

Motivators, Leisure Activities, Independent Activities:

VII. Cognitive Skills:

Test Scores that are pertinent to placement: Include name of test, date administered.

Orientation:

Memory: Implications for ability to retain information: strategies to improve memory. Use of external memory aids, e.g., daily schedule, log book.

Problem Solving:

Other:

VIII. Communication

Receptive Language: Ability to follow instructions within the classroom, need for preferential seating, need for repetition and monitoring; use of visual cues.

Expressive Language/Speech: Statement of status, how functional speech is, compensatory techniques.

IX. Academic Skills

Test Scores: Include academic test scores that are pertinent to placement and selection of materials. Provide date(s) of administration.

Suggested Modifications in Presentation of Materials: Physical modifications; preferential seating near teacher; extra time to complete work; repetition of instructions; use of daily log book; orientation to schedule; multiple choice format for checking acquisition of information; peer tutoring, study hall, general idea of number of classes that could be handled; pass-fail classes; general type of classes suggested; suggested curriculum materials; appropriateness of pre-vocational classes.

Recommendations for Class Placement: Provide this information if appropriate for the situation; Self-contained class; mainstream with resource room; regular classes with monitoring; alternative placement.

X. Therapy Recommendations

PT, OT, Speech: Amount of therapy recommended, direct service and/or consultation, anticipated sites of tx (out-patient facility, school, both), general focus of tx.

Counseling:

XI. CHMC Resource List:

Disciplines, Names of Primary Clinicians, Phone Numbers:

THERAPEUTIC COUNSELING FOR PARENTS

- **Common Feelings and Reactions**
- **Ways of Coping**
- **How to Find a Counselor**
- **Where to Find a Counselor**

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Therapeutic Counseling for Parents of Children with Special Needs

Parents have a myriad of reactions when hearing that their child has a chronic disease or disability. Often emotions come and go in a rollercoaster fashion. Many parents face accepting/hearing the news that their child has a disability, and then, at the same time, are thrown into the awesome task of taking their child home, using GI tubes for feeding, cleaning trachs and doing 100 other things they never dreamed of EVER doing, let alone doing every day. Along with all this, they are supposed to have a "normal life"--take care of the other children, go shopping, prepare meals, be a supportive, loving spouse, do community and church activities, etc. Frequently parents of children with special needs feel overwhelmed before they even get out of bed.

Common Feelings and Reactions

The following is a list of common feelings and reactions that parents and family members have after receiving the news that their child has a disability. It is intended to describe some of the most commonly cited reactions and behaviors that parents have reported in "looking back" over their own coping process.

1. **SHOCK:** Disbelief, numbness and helplessness

Possible responses:

- a. Initial difficulty taking in and hearing information being discussed.
- b. Inability to problem solve or "act on" initial information, characterized by missed appointments or refusal of services.

2. **DENIAL:** Refusing to recognize disability, rationalizing the delay, or seeking professional confirmation that there is nothing wrong.

Possible responses:

- a. Inability to accept and hear painful information, thus hearing only aspects of what has been discussed.
- b. Refusal of services for the child during this time, as the very services themselves represent an acceptance of the information being denied.
- c. Rationalization regarding the child's abilities.

3. **GRIEF AND DEPRESSION:** Grief is a necessary and useful reaction and should not be avoided; it provides a transitional period whereby former dreams are readjusted; depression is often a consequence of the grieving process.

Possible responses:

- a. General withdrawal and apathetic attitude toward services at this time, possibly extending to many aspects of life including family, friends, religion and the child her/himself.
- b. An "emotional roller coaster" with little feeling of stability or comfort; feelings ranging from exaggerated optimism to the depths of helplessness within a short time period.

4. AMBIVALENCE AND GUILT: Intensifying the normal emotions of love and anger; possibly resulting in a person showing strong dedication to some individuals and show rejection toward others.

Possible responses:

- a. Neglect of oneself and other family members, completely immersing oneself in the welfare of the child.
- b. A repeated need to talk about the child and/or the disability such as regretting possible causal factors; need for repeated reassurance that they are doing all that can be done for the child.

5. ANGER: Why me? Blaming may occur.

Possible responses:

- a. Criticism of the child's program; criticism toward certain individuals (doctors, program staff); criticism toward legislative bodies who are not doing enough.
- b. Loss of trust and of a sense of fairness about the world.

6. SHAME AND EMBARRASSMENT: Anticipating social rejection, pity, loss of self esteem, fear of embarrassment.

Possible responses:

- a. Isolation: Choosing not to participate in community groups or associations other than activities attached to the world of services for persons with disabilities.
- b. View of community-based activities as threatening at this time.

7. BARGAINING: "Striking a deal" with God, science, or anyone who promises to make the child normal; final attempts to cure the child.

Possible responses:

- a. Consideration of unusual, untested and/or experimental programs and therapies of all kinds regardless of cost or feasibility, if it is thought to be possibly beneficial to the child.

- b. Immersion in the child's program or related organizations, with the underlying assumption of "If I work hard enough..."
8. ADAPTATION AND REORGANIZATION: A gradual process requiring varying lengths of time and a reduction in the feelings of anxiety and other intense emotional reactions.
- Possible responses:*
- a. Daily routines, overall family activities, and the child's special needs beginning to settle into a more regular pattern; emotions possibly continuing to arise, but less often, not as acutely painful, and shorter.

Ways of Coping

During this very difficult time of change and transition, people often seek help from their social supports--extended family, friends, and neighbors. Parents frequently cite their faith, spiritual support, and/or support from churches and synagogues as being invaluable. Individuals often find support through community resources and professional assistance (home care providers, doctors, intervention programs, etc.).

In spite of all these resources, many parents continue to struggle with feelings of being overwhelmed with all the changes, the loss of control over their life, the strong emotions of anger, grief, guilt, fear, and constant exhaustion.

How do you untangle this confusion, pain, anger, and hurt? How can you turn things around so that your life is under some semblance of control?

For those feelings that are difficult to own, let alone express, sometimes a professional counselor provides the best resource. Professional counseling provides a safe and confidential environment in which to work with the parts of oneself and one's life that seem unacceptable. The time to do this is when your life seems to be moving out of control, and/or before you lose the willpower, the desire, or the physical capacity to cope anymore.

Counseling allows families and individuals to work through those very real feelings, fears and doubts, to experience acceptance and develop self-acceptance. Counseling is a source of trust-building, healing, self-empowerment, and increased self-esteem. It is a safe place to figure out the difficult issues of life.

How To Find a Counselor

Finding the right counselor is one of the most important choices a person can made. Think about the things that are important to you. People sometimes forget that a counselor works for them. You have the right to interview and select a counselor who meets your counseling needs, who is compassionate and provides you with hope and understanding.

Feel free to call different counselors and ask them questions. There's no charge, and a short phone call can be an invaluable source of information.

1. Consider basic choices or preferences:

- a. Do I prefer a man or a woman counselor?
- b. Do I have ethnic, religious or spiritual preferences?
- c. What kind of experience and education do I want my counselor to have?
- d. Do I have an age preference?
- e. Would I prefer my counselor's office to be close to my home?
- f. Do I have specific office-accessibility needs?

2. Once you've established your personal "counselor profile," you might consider asking a prospective counselor these questions:

- a. "How much experience do you have working with persons with disabilities and their families?"
- b. "Do you have specialized training in this area?"
- c. "How long have you been counseling people with problems like mine?" (Tell the counselor what your specific issues are. You don't need to go into detail, just give general areas. Examples include depression, divorce, sexuality issues, anxiety, anger, dysfunctional families, broken relationships, abortion, eating disorders, etc.)
- d. "What do you think you do that is most helpful to clients?"
- e. "What kind of techniques do you use?"
- f. "What is your comfort level with disabling conditions?" (Be specific: "What's your experience and comfort level with someone who is a quadriplegic, who wears a bag to collect urine, who speaks with a communicator, who has a chronic, debilitating disease, who is badly burned, etc.?"")

3. Is this counselor aware of and sensitive to disability /sexuality issues? Are they able to share sensitive information in a way that is comfortable to you?

- a. Does this person help you feel confident and hopeful about the future? Is this person interested in you as a person and in helping you move on? Are you free to talk with them about difficult or painful issues?

- b. If a counselor stumbles around, their jaw drops and they start to stutter when you bring up specific issues...keep looking! Trust your instincts. You and your emotions are valuable. You are looking (and paying) for a service and that means YOU are in charge.
- c. Look until you find a counselor who is competent, trustworthy, and accepting--a person who has the skills to empower other people, who will facilitate your healing process, increase your self-esteem and move you on to a more freeing life.

Where To Find a Counselor

Look in the yellow pages of your telephone directory under "Counselors--Marriage, Family, Child & Individual."

In King County, contact the Community Health Access Program at 284-0331 (local) or 1-800-756-KIDS (long distance) for professional counselors who work with families of children with special needs.